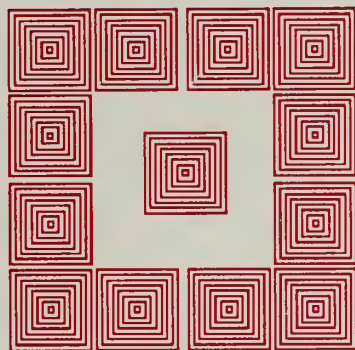


# THE CARROLL CENTER FOR THE BLIND

LEADERSHIP SYMPOSIUM  
NOVEMBER 19-20, 1986



*TOWARDS THE FORMULATION OF A NEW MODEL IN  
REHABILITATION FOR THE NEWLY BLINDED FOR THE  
TWENTY-FIRST CENTURY*

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# The Carroll Center For The Blind


770 Centre Street  
Newton, Massachusetts 02158

Leadership Symposium  
November 19-20, 1986

Towards The Formulation Of A New Model In Rehabilitation For The Newly  
Blinded For The Twenty-First Century

In celebration of 50 years of dedicated service to blinded persons by The Carroll Center for the  
Blind, (formerly The Catholic Guild for the Blind) and in honor of the Twenty-fifth year of  
publication of Blindness, What It Is, What It Does and How To Live With It.,  
by Father Thomas J. Carroll.

Held at The Ritz-Carlton Hotel  
Boston, Massachusetts



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## Introduction

All of us in the rehabilitation field are driven by pressing daily concerns: the buttressing of existing programs or reacting to proposals made to us to start new programs which would address new and future needs. Far too few of us invest the time and money to assess what we have done, what we are doing, and reflect upon what we are all about.

Because of this the Carroll Center for the Blind conducted a leadership symposium which examined whether rehabilitation ideas developed post World War II are still viable for the 80's and beyond. The symposium also stimulated thought about the formulation of a new model in rehabilitation for the newly blinded to be used for the twenty-first century.

Each one of the symposium participants examined an aspect of future rehabilitation needs and reported their finding to those who attended the symposium. Following are the speeches that were given by the participants. Each is well known in the rehabilitation field and needs no introduction.



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# REHABILITATION SERVICES TO VISUALLY HANDICAPPED PEOPLE

## Current Practices - Implications for the Future

*Penelope Shore, Ph. D.*

*Royal National Institute for the Blind: London, United Kingdom*

As perhaps you can imagine, the sense of honor and privilege that rests upon anyone invited to address this 50th Anniversary Symposium of the Carroll Center, is something of an awesome responsibility. In the first place, there is the inescapable realization that whatever one might say, whatever new insights one may slowly and painstakingly have gained, Thomas Carroll trod that same path and gave far more cogent expression to those same thoughts - and many more besides - all of 25 years ago.

I have been particularly struck in recent weeks, in reviewing Carroll's seminal writings, by a realization of how widespread his influence continues to be, and of the extent to which his thinking continues to inform and underpin much of the most thoughtful and caring work carried out today with recently visually handicapped people. That debt to Carroll, though far-reaching, is perhaps too often unconscious - the more reason, therefore, for us to be thankful for the opportunity provided by this symposium to take stock of what we have learned from Carroll's work and, most importantly, consider how we can carry those lessons forward into the future.

There is another reason too, why the responsibility of this keynote address is a particularly serious one for me - and that is the realization that I join you here at this Leadership Symposium very much as an outsider - not simply because my viewpoint is that of someone from the other side of the Atlantic, but because I am still very much a newcomer to the world of rehabilitation for visually handicapped people. What I may be able to offer, however, is not so much the "expert view" as the perspective of the outside observer - the view of a researcher whose brief it is to survey the welter of provision and examine whether the picture built up from those fragments forms a coherent pattern of service provision. My research base is, of course, the current state of rehabilitation services for the visually handicapped in the UK, but, though the circumstances of welfare provision and social structures do vary between our two countries, I hope that the issues emerging from researches in the UK will have some relevance to you here in considering the way forward.

**First premises:** Before turning to those key issues which have emerged from my research, we need to examine two basic questions in order to establish the initial premises of our dialogue. Firstly, what do I mean when I use the term "rehabilitation"; and secondly, what is different about UK welfare structures as they affect rehabilitation services for visually handicapped people?

"Rehabilitation" is the term we all use at least fifty times a day to signify the central purpose of our work. But do we all mean the same thing by it? I would venture to doubt it! The last thing I would wish to embark on is a tortuous debate on the semantic niceties involved in defining rehabilitation, and I therefore propose to offer not a single prescriptive definition but rather a choice, of several in order to share with you some of the concepts and concerns which have informed my thinking about rehabilitation.

*"Total" rehabilitation ... is the process whereby adults in varying stages of helplessness, emotional disturbance and dependence, come to gain new understanding of themselves and their handicap, the new skills necessary for their new state, and a new control of their emotions and their environment.*

*(Carroll, 1961)*

*Rehabilitation ... is a treatment process designed to help physically handicapped individuals to make maximal use of residual capacities and to enable them to obtain optimal satisfaction and usefulness in terms of themselves, their families and their community.* (Krusen, 1971)

*Rehabilitation ... consists of the restoration of patients to their fullest physical, mental and social capacity.* (Mair, 1972)

Although the second and third of these definitions are written from a medical standpoint, I have found them helpful because of the emphasis they place on individual potential.

The second piece of groundwork we need to complete before going any further, concerns the question of differences between administrative and

social welfare structures in the UK and the USA as they relate to rehabilitation services for the visually handicapped. The simplest way of doing this is to outline briefly the way things happen - or are supposed to happen - in the UK, and let you draw your own conclusions about similarities and differences here in the States.

**The Framework of UK Services:** If we were to confine ourselves simply to a review of legislation, the situation would appear relatively positive. The blind were the first group of disabled people in the UK whose specific needs were recognized by a special, separate Act of Parliament: the Blind Persons Act, 1920. The provisions of that earliest legislation have subsequently been adapted and augmented in later Acts concerned with the welfare of disabled people in general, particularly the 1948 National Assistance Act; the 1958 Disabled Persons (Employment) Act; the 1970 Chronically Sick & Disabled Persons Act; and most recently the 1986 Disabled Persons (Services, Consultation & Representation) Act.

But how well does this wealth of legislative provision appear to work from the point of view of an adult person recently affected by sight loss? If I were in that position, I think I should feel as though I were caught up in a jungle: a situation in which a plethora of services appeared to be available from a multiplicity of agencies, with the problem of having to discover by trial and error who to turn to for which kind of help, or, worse still, having no information whatever and hence no idea what help might be available and no knowledge of the possibilities of rehabilitation.

Perhaps the main problem, currently, is that there is no single agency effectively exercising responsibility for coordinating the range of statutory and voluntary medical and social resources involved in the rehabilitation process, and guiding the visually handicapped person to the help available to him. Instead, visually handicapped people will, all too often, have to discover for themselves a way through the maze of social administration that consists of the following separate systems:

**National Health Service (NHS):** for eye care - diagnosis, treatment, prescription and provision of Low Vision Aids. Referrals must be from a neighborhood General Practitioner to a Hospital Consultant Ophthalmologist. There is a chronic shortage of Low Vision Clinics, even within those hospitals with well developed ophthalmology departments.

**Local Government Social Services Departments (SSDs):** for services that are labelled "social rehabilitation", i.e., assistance in initial adjustment to blindness, information, advice, counselling, practical skills training (daily living skills, mobility, communications).

**Manpower Services Commission (MSC):** This is an agency of central government, responsible for all employment-related issues nationally, and with specific regard to visual handicap, responsible for vocational guidance, assessment, vocational rehabilitation, further vocational training (e.g., engineering, telephony, office skills, computing) as well as job placement. RNIB acts as MSC's agent for many of these services, but is largely dependent upon MSC's national network of local Job Center offices for the great majority of referrals.

**Voluntary Societies for the Blind - local and national:** for advice and information, provision of special aids, provision of social and recreational activities, agency services for statutory bodies, e.g., SSDs and MSC.

The roles of these various statutory and voluntary bodies may appear to be relatively clearly defined - but the problems for the visually handicapped person arise from the lack of effectively coordinated interaction between them. Thus, for example:

(a) The first a Social Services Department is likely to know of a visually handicapped person who is in need of assistance, is when a referral is received from a Consultant Ophthalmologist in the NHS saying that the person is eligible for registration as blind or partially sighted. That person may have been visiting hospital as an out-patient for months, or possibly years, receiving excellent medical treatment, but probably grappling unaided with the practical and psychological problems that sight loss can bring, and perhaps falling - understandably - into the traps of functional or emotional dependency, and maladjustment to sight loss.

(b) The first the MSC and its special Disablement Advisory Service may hear of the special needs for rehabilitation and vocational guidance of a visually handicapped person is when, for example, a young or middle aged man, perhaps with retinitis pigmentosa or diabetic retinopathy, walks into his local Job Center to register as unemployed, having already lost his job because of failing sight.

In other words, what help is available - and many of us in the UK would argue that it is far too little - almost invariably arrives far too late. In the UK,



the newly blind person is all too often in the position of the drowning man so memorably described by Dr. Johnson, for, having struggled to save himself by his own efforts, he finds that once the crisis is past and the shore safely regained, he is encumbered with assistance that is by then irrelevant to his needs.

Arguments can be put forward to demonstrate that responsibility for coordinating this fragmented miscellany of provision rests in the UK with the Local Government Social Services Departments - and it is certainly true that the new 1986 Disabled Persons Act clarifies and reinforces the Social Services Departments' responsibilities in this area. But the fact of the matter is that for a variety of historical, professional and economic reasons, the Social Services Departments are currently not in a position to undertake this role effectively. This statement is certainly borne out by the findings of the survey which I undertook for RNIB in 1983 of a proportionately stratified sample of Social Services Departments in England and Wales (Shore, 1985). For example:

- **not one** of the Authorities surveyed had formulated a statement of their policy on the provision of services to the visually handicapped.
- **only 16%** of the sample had taken any action to investigate the needs of visually handicapped people within the 7 years prior to the survey, and in only **5%** had any action been taken to implement the findings of such investigation.

In terms of services actually provided to people recently registered as blind by the Social Services Departments the survey showed:

- **36%** of respondents had **NOT** been offered any information about services and benefits available to them.
- **57%** had **NOT** been offered any practical rehabilitative training.
- **82%** had **NOT** been offered any advice or counselling about their feelings toward sight loss.

Looking more closely at practical rehabilitative training, that is; daily living skills, communication skill, and mobility, we found:

- **43%** of those who were offered training said they **needed more**.
- **52%** of those **not offered** training said they **would have liked training**.

Whether or not a blind person was offered any kind of rehabilitation service depended largely, in our

sample, upon two primary factors: age and location. Whereas 90% of respondents aged between 20 and 49 had been offered rehabilitation, only 31% of those aged 65+ said they had been offered the same opportunity. With regard to location, the survey revealed that a blind person's chances of being offered a rehabilitation service were affected not only by which Social Services Department was responsible (i.e., whether or not that agency maintained a specialist service for the blind), but also in some instances by his precise location within a given SSD area. In other words, the availability of rehabilitation services varied widely not only between SSD but also within these agencies, reflecting poor planning and management in the deployment of existing specialist manpower resources.

Variation in service levels **between** LAs was, of course, not unexpected, and this trend is most immediately reflected in the numbers of specialist staff employed by a SSD in relation to the size of the known visually handicapped population. The ratio of visually handicapped people to specialist workers ranged within the sample from 146:1 to 987:1.

When these figures are compared to the unofficial rule of thumb formerly applied to the appointment of Home Teachers (200:1 in rural areas or 250:1 in urban areas), we find that:

- in **more than two fifths** of SSDs (42%) the actual numbers of visually handicapped people to specialist workers were **more than twice as high** as recommended levels (i.e., 400:1 and in some cases higher).
- in **more than one quarter** of SSDs (26%) the client:staff ratios were **up to four times higher** i.e., 800:1 - 1,000:1).

When we focused attention specifically on the employment of mobility officers, we found that:

- **over one quarter** of SSDs (26%) **DID NOT EMPLOY** a M.O. at all.
- **more than one fifth** of SSDs (21%) had client:mobility officer ratios **in excess of 1,100:1**.

Examining other factors which also reflect the quality of services available to visually handicapped people, we found that amongst the Social Services Departments surveyed:

- **64%** did **not** provide information leaflets, detailing services and benefits.

- 51% did not provide an initial specialist assessment for all newly referred visually handicapped clients
- 68% did not provide day centre rehabilitation programs

Overall, if we postulate that the minimum requirements for "good practice" involve:

- direct and integrated access to qualified social work and rehabilitation services
- provision of initial specialist assessments for all new referrals of visually handicapped people
- reasonably adequate numbers of specialist staff, including mobility officers

then, at most, only 21% of Social Services Departments surveyed could be cited as examples of "good practice".

Perhaps even more disturbing as an indicator of future standards of provision for the visually handicapped was the fact that the survey revealed very little evidence of current or planned development by SSDs of their services to visually handicapped people. It was particularly apparent that the widespread commitment to local, as opposed to national residential social rehabilitation services, was not matched in practice by any concomitant development in provision at the local level for people who lose their sight in adult life. Indeed, the survey revealed evidence of further deterioration amongst Social Services Departments with already low levels of provision (Shore, 1985, 3.14; 6.23; 7.15).

Other research commissioned by RNIB in the last 3 years is augmenting this evidence of the effects of fragmented, uncoordinated provision of services for visually handicapped people, particularly in relation to their employment prospects.

Firstly, in an unpublished study on employment trends as they affect the visually handicapped, undertaken on behalf of RNIB in 1985, Dr. Graham Lomas, estimates from the available data, that the unemployment rate for visually handicapped people in the UK, will be around three times higher than the rate for the general population, i.e., 49% instead of 15%. Secondly, a recently published RNIB survey of visually handicapped job-seekers (Whaley et al. 1986) found that only 17% of people who lost their sight while in employment sought specialist vocational guidance before giving up their job because of their disability. Thirdly, current research into the characteristics and rehabilitation outcomes of visually handicapped people attending the RNIB

National Rehabilitation Centre, indicates that the number of people aged 16-49 officially recorded as newly blind each year is more than three times higher than the number of places annually available at that center - the only one of its kind in England and Wales.

Such, then, is the picture of fragmentation; lack of clear coordination, shortage of resources, and variation in standards of practice, which emerges from a brief overview of the current state of rehabilitation services for visually handicapped people in the UK - perhaps some of the elements of this overview exist in the USA.

The issues emerging from such an overview are, of course, legion, and though time will not permit us to consider them all, I propose to examine a number of them in turn, whilst considering what implications they hold for us in our determination to develop and improve rehabilitation services for people with visual handicaps in the future. Some of these issues, listed in Figure 1, relate primarily to the quality and practice of rehabilitation at the levels of interface between the professional worker and the visually handicapped person (e.g., 1 & 2). Others are of concern essentially at the strategic level in the policy making and organization of rehabilitation services (e.g., 4 & 5). Some issues, of course, span both the micro and macro levels of the rehabilitation continuum (e.g. 3).

**Figure I**

**Issues**

1. **The Reduction of Rehabilitation** to training in practical skills.
2. **Assessment:** growing recognition of importance but shortage of skills.
3. **Ageism:** macro-resources concentrated on working age group.  
micro-attitudes of workers and elderly people themselves, mutually reinforcing low expectations.
4. **Fragmentation of Rehabilitation Services/** Proliferation of Service Agencies.
5. **Specialism:** concentration and promotion of expertise and resources, or segregation and isolation?
6. **Rehabilitation and Self-Determination:** for Rehabilitation Worker and "Client" alike the goal is independence. **BUT** who controls the process?
7. **The "Clinical Model of Rehabilitation:** Framework or constraint in integrating the visually handicapped person and society?

**Strategies for Response**

1. The Dissemination of Research Awareness-raising /Training Coordination of expertise/ Multidisciplinary working.
2. Research dissemination/training.
3. Consciousness-raising/ Advocacy/ Public Education/ Applied Research - dissemination.
4. Coordination/Interagency co-operation/Inter-disciplinary working/Dissemination of Research - e.g., Rehabilitation Consultancy Service.
5. Multidisciplinary Working/Inter-Agency Collaboration/ Inter-Disability Collaboration.
6. Professionalism Prescriptive or Facilitative? Self-Help.
7. Rehabilitation Agency as Advocate/Lobbyist as Public Educator.



**1. The Reduction of Rehabilitation to Practical Skills Training:** or, rehabilitation as a skills dominated process. Twenty-five years ago Carroll wrote:

*Without an attack on the external problems of blindness, any work on the inner problems has little likelihood of success; and, equally, without work on the inner problems - on total personality organization - work on restoring skills and capabilities is of little value."* (Carroll, 1961)

But, despite the example of Carroll's work, despite what you might think common sense and the lessons of ordinary human experience might have to tell us, the sad fact is that in the UK "rehabilitation" as provided by the key service-giving agencies - the Social Service Departments - has become for the most part a process dominated and preoccupied by practical skills training and the provision of technical aids to daily living. It is as if the providers of rehabilitation assume that by teaching the newly blind person to be a competent brailist, a safe cook, or a proficient long cane user, the rehabilitation task is complete.

As I pointed out earlier, in many instances in the UK, a recently visually handicapped person would be lucky to receive that much in the way of "rehabilitation". All too often, because of the lack of trained employees in SSDs, the provision of practical aids has to serve as an inadequate substitute for skills-training. It may be that the scarcity of trained manpower in SSDs has tended to magnify our concern and pre-occupation with this practical aspect of rehabilitation. Nevertheless, the fact remains that in our 1983 survey only 18% of recently registered blind people said they had been offered any advice or counselling about their feelings towards their loss of sight.

There is mounting concern in the UK about the inadequacy of our rehabilitation services in this respect. The agencies responsible for the training of workers in the field of visual handicap have taken steps to strengthen the counselling skills component in their training courses, and research has been undertaken into the need for counselling amongst people newly affected by sight loss (Conyers, 1986). Research of this kind has to be seen not as a means simply of adding a veneer of academic credibility to what you may take to be the abundantly self-evident, but rather as an instrument which will help strengthen our bid in the competition for scarce and diminishing resources.

Research, and above all, the effective dissemination of research findings, needs to be one of the strate-

gies we adopt to correct this imbalance in current rehabilitation provision. The research in itself, however, will be of little value if it is left on the shelf to gather dust. The tricky part of the exercise is how to use the findings of that research to change people's perceptions and attitudes; to strengthen the validity of our claims for resources and thereby - we hope - produce a tangible and positive effect on the quality of services.

No matter how optimistic those of us with academic tendencies may be about the efficacy of research, that strategy alone is unlikely to solve all our problems. No matter how convincing our research evidence, there is in the late 1980's little realistic probability that we will be able to spend our way out of our difficulties, for example by appointing even more staff to meet newly emerging needs. Resources are finite, and many others will believe they have as good a claim to a bigger slice of the cake as we have. Instead of expecting always to identify new resources, whether of cash, accommodation or expertise, our strategy may need to be one of identifying existing resources that can be used in new and more effective ways. This may mean looking at familiar things within our own agencies, facilities, procedures, etc., from an unfamiliar angle - or it may mean looking in unexpected places outside our normal sphere of activity for what we want. It means making connections and pooling resources - resources of information and expertise as well as concrete facilities; it means multidisciplinary working and interagency collaboration.

For example: two of the strategies we are beginning to consider in the UK to improve the availability of counselling services for recently visually handicapped people are, firstly, to promote joint funding by local partnerships of SSDs and District Health Authorities for the appointment of social workers/counsellors to hospital eye clinics, and, secondly, to exploit the potential of existing counselling services developed in other fields - e.g., Samaritans, Cruse (an association for the bereaved) - so that they may develop an appreciation of the problems of adventitious sight loss and a commitment to apply their skills to the assistance of visually handicapped people.

I have spent some time elaborating on these two strategies of Research Dissemination and Multidisciplinary/Interagency working, because those strategies recur here and throughout the symposium program as the key means of responding to some of the more problematic issues in current rehabilitation.

**2. Assessment:** The second issue emerging from our consideration of current rehabilitation practice, like the first, is concerned primarily with the practice of rehabilitation at the interface between worker and the visually handicapped person. Assessment is an issue currently much vaunted in the UK - in recognition partly of the concern to ensure that the rehabilitation service offered is appropriate to the needs of the individual blind person, and partly also in recognition of the scarcity of resources and the need to ensure that available expertise and facilities are channelled where they will have greatest effect.

Statements to the effect that the rehabilitation services provided are "all based on the client's individual needs" are frequently heard in the UK from rehabilitation practitioners and their managers - but in reality this impressive credo is undermined by two factors: firstly, the lack of specific assessment skills on the part of practitioners (Dodds et al. 1986); and secondly, the tendency to base "assessment" on a checklist of the agency's available resources rather than on the actual needs of the blind person - i.e., an "agency-centered" rather than a "client-centered" process.

What strategies appear to be indicated by this issue? Clearly, as Dodds and his colleagues have indicated, further research in this area is required, although, to be responsible and productive, such research should fulfill two primary requirements. Firstly, it should be interdisciplinary in character: we do not have time to re-invent the wheel when we can learn from the expertise developed in other fields. Secondly, the results of further research must be effectively disseminated: so that it is assimilated into training programs for new and practicing workers; and also so that it is targeted to influence the awareness of resource managers and planners and thereby enable the findings of a systematic process of "client-centered" assessment to have a direct impact on the range and character of services available.

**3. Ageism:** This issue relates to work both at the level of interface with the visually handicapped person and at the strategic level of policy and organization. Three-quarters (75%) of the registered blind and partially sighted population in the UK are over 65 years of age and more than half the total are over 75 years of age (57%) (RNIB, 1985). They are the visually handicapped majority. The main causes of sight loss in the UK are the degenerative eye diseases of macular degeneration, senile cataract and glaucoma, whose incidence is associated with the aging process. The equation is perfectly simple: the higher the proportion of elderly people in the general population, the greater the incidence and

prevalence rates of visual handicap. In the UK it is now becoming generally recognized that the most significant demographic change to occur in the next 25 years will be the dramatic growth in the size of the elderly population.

Despite the demographic and epidemiological realities, there can be little doubt that elderly visually handicapped people, in the UK today, are doubly disadvantaged: firstly, because of their visual handicap and, secondly, because of their age. In those agencies primarily responsible for their welfare - the local government Social Services Departments - visual handicap is an area of work accorded low status and low priority, and work with the elderly is all too often regarded in exactly the same light.

As indicated earlier, the findings of our 1983 survey showed that opportunities for rehabilitation were likely to be significantly reduced if a recently registered blind person were aged 65 or over: in fact, 90% of respondents aged between 20-49 had been offered rehabilitation, but only 31% of those aged over 65 said they had been offered the same opportunity. In one area of the country, for example, where 90% of newly registered blind people were over 65 years of age, rehabilitation staff reported that only 1% of new cases were in their opinion likely to require training in either daily living skills or braille (Shore, 1985). The catalogue of discriminatory attitudes towards elderly visually handicapped people could be considerably extended.

What the evidence points to is not malice aforethought on the part of rehabilitation workers, but rather the insidious but pervasive effects of the negative stereotypes of elderly people endemic in our society. Stereotypes which insist that elderly people are incapable of change - unless, of course, change is taken only to signify deterioration, loss of faculties, and decay - stereotypes which discount any possibility of individual potential. It would, of course, be foolish and counter-productive to ignore the very real limitations which old age and its associated disabilities can impose, but, as Olive Stevenson, Professor of Social Work Studies at the University of Nottingham, has argued that, understanding "is an entirely different matter from a blanket assumption that the opportunities to learn and to adapt offered to younger people are inappropriate for the old". (Stevenson, 1985).

The effects of these ageist stereotypes inevitably color not only our own attitudes but also those of elderly people themselves. How often is the complacent attempt at sympathy enshrined in the words, "Well, what can you expect at your age?", echoed



by the adoption of similar statements of stoic resignation by an elderly person himself - "It's what you expect when you get to be my age". Understandable though this may be, the danger is that such collusion reinforces negative attitudes and thereby creates a downward spiral of low expectation - which in turn affects the range and character of services deemed appropriate by practitioners, policy makers and planners alike.

Thus, the effects of ageism at the level of individual interaction can scarcely be separated from those which are manifest at the macro level - in the structure of rehabilitation services and in the allocation of costly manpower and material resources. Thus, in the UK, for example, central government funds are only channelled via MDSC into rehabilitation services for people of working age, while in the local government Social Services Departments, as we have already seen, rehabilitation resources also tend to be concentrated on work with the younger visually handicapped minority. Even in the voluntary sector, there is still need for us to question whether we are doing enough to help elderly visually handicapped people. At the present time there appears to be no real equivalent in the UK to the Grey Panther movement in the United States, but there may well be a case for affirmative action to counteract the logjam of negative and discriminatory ageist ideologies.

What then are the strategies we need to consider in responding to this issue of ageism? I am hoping to learn a lot from you, not only here at this symposium but also during the remainder of my stay in America. The signals coming across the Atlantic suggest that you are already finding ways of grappling with problems in this area - signals such as the research on the quality of life of elderly visually handicapped people conducted by Gillman and his colleagues (Gillman et al, 1986); the new community guide to vision and aging, A Better View of You, issued by the National Center for Vision and Aging, as well as the self-help materials published in 1982 by the American Foundation for the Blind, What are Friends for?.

My assumption, however, is that the kinds of strategies we will need to adopt in the UK will have to begin with some very basic consciousness-raising, followed by advocacy, public education and more applied research, dissemination of the research findings, consciousness raising and so on - the process forming a continuing cycle of renewal and development.

#### **4. Fragmentation of Rehabilitation Services/Proliferation of Service Agencies:**

You will by now have formed a pretty clear impression of the effects of the fragmentation of rehabilitation services in the UK; of the artificial organizational divisions between social and vocational rehabilitation, and of the gulf that all too commonly exists between ophthalmological and optometrical services and other aspects of rehabilitation.

I shall be particularly interested to learn during my stay in the States of the extent to which these kinds of artificial distinctions between one professional discipline and another, or between the roles of one agency and another, also affect the rehabilitation scene in this country. And I hope, too, that I shall take back with me some new ideas about ways of crossing these professional and organizational boundaries and establishing more fruitful interchange between what were once separate and jealously guarded territories.

Clearly, when we come to consider the strategies that need to be developed in responding to this issue, multidisciplinary working and interagency collaboration must come high on the agenda. I feel sure I will have a great deal to learn on these topics from my visit to the United States - but it may interest you to hear briefly about one of the ways in which RNIB is beginning to tackle this problem of fragmentation in the UK.

In the light of my researches on Local Authority Social Rehabilitation Services, RNIB is now launching a Rehabilitation Consultancy Service which will aim to stimulate the development of statutory social rehabilitation provision by:

- providing information and advice to Local Authorities on the rehabilitation needs of visually handicapped people and on the implications which these have for the future development of services.
- fostering communication and cooperation between the various professional groups concerned with the welfare of the visually handicapped in the health services, education services and social services as well as with the voluntary sector.
- fostering and disseminating good practice in the provision of rehabilitation services amongst local authorities.

In short, by influencing the attitudes of senior managers in social services departments, by heightening awareness and raising the profile of visual handicap, and by promoting multidisciplinary and interagency collaboration, we hope to see visually handicapped people achieve a higher priority



with the policy makers and planners, and obtain a higher standard of rehabilitation service.

**5. Specialism and its implications for strategic policy:** the next issue I would ask you to consider is the notion of "specialism" and its implications for strategic policy. In the UK, as I have mentioned, the visually handicapped were the first group of disabled people for whom special provision was made by a separate Act of Parliament in 1920. The visually handicapped have long been recognized as a special group of people, with particular special needs, requiring specialist expertise and highly specialized resources to deal with them. In the past, we have tended to regard "specialism" as a desirable and necessary goal: as the pursuit of excellence; as the concentration and promotion of sought-after expertise and resources. But the question we are now having to ask ourselves in the UK is whether this approach may in fact be leading us down a very narrow path that will eventually turn out to be a dead-end?

On the macro-level of strategic policy and organization, just how narrowly and exclusively "specialist" can we afford to be? Let's face it, the registered visually handicapped in the UK make up no more than 0.04% of the general population, and that is hardly the kind of figure that will sway the policy makers and planners, particularly at a time of economic constraint and diminishing resources. But, if we can stop thinking exclusively of the factor of visual handicap and point out that in some parts of the country the prevalence rates for visual handicap will be as high as 1 in 25 or even 1 in 15 amongst people over the age of 65, or that many visually handicapped people also have additional handicaps or chronic illness; that, for example, amongst mentally handicapped people, the prevalence of visual handicap may well be ten times higher than in the general population (Ellis, 1982) - then we may begin to develop a much stronger case, albeit one dependent upon cooperation and interaction with agencies representing the interests of other groups in the community, whether of the elderly, or the physically or mentally disabled.

We may also need to consider the issue of "specialism" at the micro-level, in relation to the effects of a narrowly based, segregated service on visually handicapped people themselves. We may need to ask whether specialism of this kind can be congruent with concepts of normalization expounded by Wolfensberger and others? (Wolfensberger, 1972). Do the majority of people requiring rehabilitation services wish to wear the label "Blind", with all the possible connotations of dependency and social stigma which that label still

regrettably carries? Or do they mostly prefer to think of themselves as perfectly ordinary people who happen to have little or no sight, and who would appreciate finding ways of coping with that situation?

A large proportion of people who lose their sight in adult life will, of course, have disabilities in addition to their visual handicap: 47% of clients at RNIB's rehabilitation centre have one or more additional handicapping conditions alongside either a visual or a dual auditory/visual loss. So perhaps we should ask whether it makes sense to isolate our treatment of the visual handicap as virtually a separate entity, or whether it may be preferable to integrate that rehabilitative provision with other kinds of "special" assistance for the problems of hearing loss, poor health or physical or mental disability, that may all contribute to an individual's own unique complex of circumstances.

In other words, our strategy should perhaps be to look more widely outside the confines of the established "specialism" to other sources of expertise and assistance - and increase our capacity to respond to that multiplicity of need by developing multidisciplinary working practices and interagency collaboration, for example, with agencies providing services for diabetics, stroke patients, the mentally handicapped, or the elderly.

**6. Rehabilitation and Self-Determination:** The sixth issue which I should like to examine seems to me to follow on from consideration of specialism, because like that issue, it concerns our perceptions and attitudes towards our work in rehabilitation and towards visually handicapped people themselves. This issue really devolves from the question, "To what extent are rehabilitation and self-determination congruent?". The goal of independence should presumably be central to each concept - but are the means of achieving that goal compatible in both instances?

Any agency or individual worker involved with the rehabilitation of visually handicapped people is likely to espouse the view that, by offering practical skills training, emotional support, counselling and guidance, they will be able to help a visually handicapped person to regain his self-confidence, self-esteem and independence. But can we feel confident in all instances that the stance of that agency or individual worker is actually conducive to independence? Or will it in fact tend to produce another form of dependency? The resolution of this issue is especially critical, not only because it is so central to the meaning of the rehabilitation task, but also because it is potentially so threatening both to the

receptor of rehabilitation - the visually handicapped person - and to the rehabilitation agent - the professional worker and his/her employing agency.

The division between non-possessive support and encouragement on the one hand and benevolent but ultimately stifling paternalism on the other can be a very narrow one. It may be that our rehabilitation work can sometimes unintentionally cross the invisible boundary separating the facilitation of independence and self-determination from the exercise of a more directive, controlling influence on the life of the client. It may be helpful to ask whether rehabilitation is to be regarded as a prescriptive didactic process, in which there must always be a right way and a wrong way for the client to perform a given task; or whether it is a more facilitative process in which the disabled person discovers his or her own most effective techniques for coping with life. In the first model, power is vested in the rehabilitation professional, who may adopt the role of director. In the second model, however, the worker's function is that of a facilitator in a learning situation in which control remains with the disabled person, who may make the key decisions about what skills to learn, how and when - a situation in which there is at least a balance of power between the two protagonists.

There is, of course, a growing militancy amongst all groups of people with disabilities: a tendency to reject the notion that those in the caring professions always know what is best, as well as pressure to demystify the scientific terminology of rehabilitation and reject what, in England, Simon Brissenden has called "dustbin language". (Brissenden, 1986). This is the mode of speech which conveniently consigns people to the depersonalized, dehumanized collectives of "the mentally handicapped", "spastic", "the disabled", "the blind", and so on, like so much trash in society's garbage can; language which actually contains the hidden message, "let's do everything we can to forget we are talking about real people".

There are now signs in the UK that a shift in the balance of power is starting to take effect, with disabled people beginning actively to claim greater rights for self-determination. A landmark in this process was achieved in 1986 with the successful passage through Parliament of the Disabled Persons Act, which enshrines in statute the right of disabled people to take an active part in the assessment of their needs by social service and education agencies, and which also confirms their right to be consulted and properly represented in matters affecting their welfare. I should perhaps explain that even before the passage of this Act, visually handicapped

people themselves held the majority of seats on RNIB's Executive Council, so that, although our title is the Royal National Institute for the Blind, we are in fact governed by visually handicapped people.

There are of course, as is well known in the United States, other means of shifting the balance of control within the rehabilitation process towards the visually handicapped person, means such as the development of peer-support and self-help which are not wholly dependent upon the attitude, insight, self-awareness and skill of the individual rehabilitation practitioner. These are approaches which appear to me to be under-developed in the UK at the present time, and I hope to learn a good deal in these areas to take back with me from my stay in the United States.

**7. The "Clinical" Model of Rehabilitation - Framework or Constraint?:** This, the final issue, which I should like to bring to your attention, stems directly from Professor Joseph Stubbins's critique of the prevailing clinical model of rehabilitation (Stubbins, 1986). In summary, Stubbins questions the validity of an approach to rehabilitation which is focussed entirely upon effecting change and development in the individual client - in the way that a doctor attempts to treat a patient, or a psychologist tries to effect adjustment in the mental outlook of his client.

Stubbins's contention is that action directed solely at developing or enhancing the skills or adjustment of the individual cannot necessarily solve all the problems, since the individual does not exist in a vacuum. Other factors impinging upon his ability to function are brought about by his relationships with family and society in general, as well as by economic and environmental realities outside the individual's control. A crude example of the limitations of the clinical model might be where rehabilitation has produced a highly efficient, blind machine operative, with excellent guide-dog-assisted mobility, for a society in which safety- at-work regulations have a discriminatory effect upon the employment of disabled people and where there is a general intolerance of guide dogs on public transport!

Stubbins argues - just as Carroll did 25 years ago - that there is a need for rehabilitation agencies to address wider issues than the client's personal skill level and adjustment. At the micro-level, for example, this could include the need to consider rehabilitation as a provision for the family unit, rather than for the handicapped individual; whilst at the macro-level, strategies such as involvement in the



formulation of environmental policies, or the promotion of affirmative action in employment and education may be indicated.

**Conclusion:** In reviewing the seven issues considered here, it is apparent that two principal strategies have dominated consideration of the implications which these issues hold for the future development of rehabilitation: the appropriate application and effective dissemination of research, and the need for multidisciplinary and interagency working methods (Figure 2).

It seems to me that the essence of these two strategies is already at the heart of the impressive symposium program that lies before us (Figure 3). Implicit in the dissemination of research lies recognition of the need for good communication, for the sharing and advance of knowledge; whilst central to the concept of multidisciplinary or interagency working is the readiness to collaborate, to break down professional and organizational barriers, to stimulate the interchange of skills and resources and thereby generate and extend the common fund of professional expertise that we will need to draw on if we are to carry forward the development of rehabilitation services for visually handicapped people into the future.

The aims of communication and collaboration are surely central to the purpose of every delegate in attending this 50th anniversary celebration of the Carroll Center for the Blind. Thus, from my "outsider's viewpoint", it appears both inevitable and self-evident that **communication** and **collaboration** will form the keynotes of a symposium such as this - and I very much look forward to joining with you in this process.

Figure 2

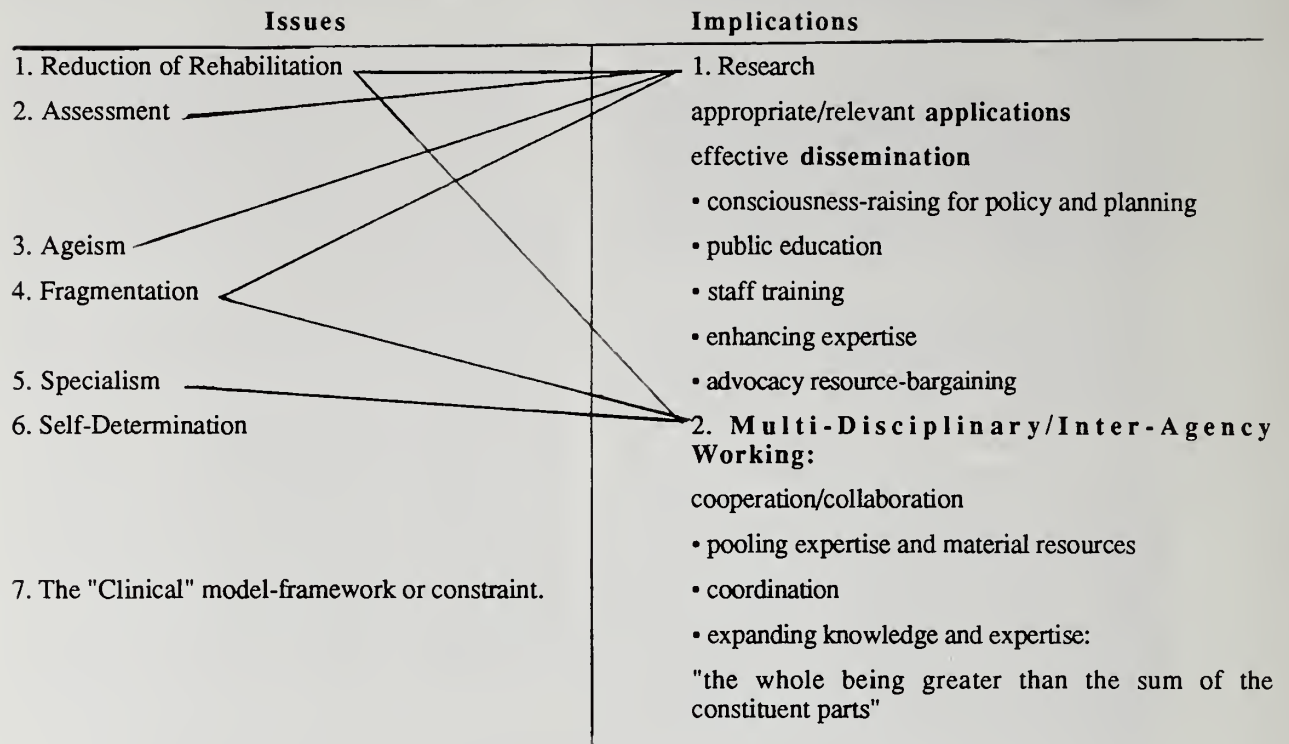


Figure 3

**Implications**

**Keynotes**

Research

Application and Dissemination -----> Communication

Multidisciplinary

Interagency-----> Co-operation

Approaches

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# CARROLL'S THOUGHTS FOR THE TWENTY-FIRST CENTURY

*John J. Muldoon, Ph.D., Clinical Psychologist  
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The task that has been given to me this morning is to discuss Father Carroll's relevance for the 21st century. It probably is an opportune time to do it. We celebrate now the 50th anniversary of the Catholic Guild and its various successors. We celebrate the 30th anniversary of the founding of St. Paul's, the 25th anniversary of the publication of Father Carroll's book "Blindness" and the 15th anniversary of his death.

There seems to be no doubt that Father Carroll was relevant for his times. I have said elsewhere that probably no other person was more important to the development of blind services today than he, with the possible exception of Helen Keller. Certainly, his footprints exist throughout the services delivery system in this country. It remains a question whether or not he is relevant for the 21st century. Were his thoughts simply relevant to the issues of his day, or do his thoughts and ideas have relevance to the problems of the blind no matter where they be, no matter what time period? I will make the case that his thoughts would be relevant today and certainly could be guides for us in the next century. I will talk about Father Carroll in a number of different roles, about his ideas, and then try to draw them together at the end by discussing what I think may have been the principles which guided his behavior and recast his concept of psycho-social rehabilitation in more sociological or organizational terms.

Father Carroll, as I look back on his life, had three roles; that of the **writer**; that of the **worker**; and that of the **advocate**; and I think in each of those roles we can see some ideas and some behavior that could serve as models for action as well as reflection.

I will talk about Father's role as an advocate. I'll talk about his unique definition of blindness. I will talk about his client-centered ideas, about service. I will talk about his emphasis on the importance of specialization of programs within the field of blindness. I will talk about his emphasis on the quality of service, and then last, in summation, I will talk about his ideas about where a rehabilitation program should be.

Let me begin with his role as advocate. I roughly divide his advocacy activities into two periods: the

early and the late. In the early period, which was really his formation period, his advocacy was directed for the benefit of individuals and it was directed to the individuals themselves as well as to those who would be their helpers. In the later period he was addressing the system advocating better services, on a state and national level rather than with individuals. He became an advocate out of his early experiences. Remember, he started out as an assigned worker to the Catholic Guild for the Blind. It wasn't his choice. Then he was assigned to Perkins School, and then he volunteered to be an auxiliary chaplain to the military installations serving the war-blinded. So with one agency he became familiar with the elderly blind. He became familiar with the attitude that the responsibility of the agency is to make blind people happy: being that they can't see, at least we can make them happy.

At the Perkins School he became familiar with what was one of the outstanding programs of the day. It was wealthy, it was well staffed, it had a good reputation.

When he went to work with blinded servicemen, he became familiar with young people who had become blind, and he became familiar with the bureaucracy that is needed to support services to help the blind. In this context, I think it was his military experience which led him to become a most important advocate for services for the blind. There in his role as chaplain he didn't have a responsibility to be helpful in the professional sense. He had a role to exercise his responsibilities as a chaplain, counselor, and good listener. This became an important experience because he began to understand blindness as it is experienced by those who became blind. If you read his book, so much emphasis is on the meaning of blindness to the person helping blind persons, i.e., not understanding blindness, but understanding persons who become blind. We will talk about this again as I think that is one of his most important contributions--the importance of understanding people who become blind rather than understanding blindness.

He also became an advocate to the better sides of the veterans, that is, he reminded them of their pride, of their values, of their ambitions, and helped energize



them to do something for themselves. In advocating services for the blind, he advocated the responsibility of the government to provide good services, but he also advocated the responsibility of the blinded veteran to take advantage of it in a reasonable way. At one time, he actually testified against the provision of special benefits to the blinded veterans because he felt that they did not deserve anything more than what the other disabled veterans had. He thought that, if they became special, they would become isolated and they might become more dependent, but he had a special place in the hearts of the veterans because he did advocate them to be motivated by their higher ideals and to make something of themselves.

I recently attended a meeting of the Blinded Veterans Administration, my first, and I was impressed with the quality of the veterans and how they took charge of their lives and were very proud of what they had accomplished. Their memory of Father Carroll is about those issues when Carroll continuously stirred them up to do something that was responsible and of which they would be proud. I think you'll see that throughout his book, he calls upon blind persons to also be proud and to be independent.

**Carroll's definition of blindness:** Carroll placed great emphasis on being objective. As a product of the 20's and 30's, he was influenced by the philosophy of the times when the logic of science was rather simple-minded and there was great emphasis on being objective and in thinking things through. We therefore find a great deal of emphasis on objectivity and being scientific. However, Carroll's definition of blindness is basically a subjective one. He is continuously looking at the reaction of the person to blindness. Now, he may be making it objective in the sense of describing it in terms of 20 losses. But, when you read the losses, there is always a sentence in there that says each person experiences this loss in a unique way, going back to the subjective. He says there are 20 losses, but he includes a section that gives concomitant losses, as if he hadn't really closed the book on the way blindness affects a person but he wanted, at least, to have a handy number.

**Carroll's approach is client-centered.** He continuously emphasizes the meaning of blindness to the person, and that leads to a different emphasis on what the client needs and wants. Carroll existed in a time, and the times are still present, when we tend to look at rehabilitation in what could be called the educational model or the medical model. I prefer to call it the mechanical model, such as when you consider the problem of maintaining your car. If something goes wrong with the car, you take it to

the diagnostician and the diagnostician, if he's good, correctly diagnoses the problems and arranges for some treatment, and, if everything goes well the car works right. In this process the car is assumed to be passive. We do not depend on the attitude of the car. We don't expect any cooperation from the car. In much of medicine we take the same approach; that is, if you have appendicitis, you present yourself to the physician who accurately diagnoses it. You present yourself passively to the surgeon who operates, and you really do not have to do too much to get better. That model works or seems to work in some instances, but, in any instance where the cooperation of the patient, the attitude of the patient is important, it falters. So the model in rehabilitation is often the same -- we, the experts, describe what the person needs and then we set up a series of services for the person and assign the person to the services. We assume that the person will be passively well motivated. As a matter of fact, if he doesn't conform, we're apt to dismiss him for being unmotivated or unready for rehabilitation.

**Carroll here separates himself from the prevailing forces.** Carroll's approach was different. Carroll thought of blindness as being a particularly unique experience and that, if you wanted to present useful efficient services, you had to understand the meaning of blindness to the person, and that consequently, you approached it by developing services in a way of helping that would energize and enable the person to take more responsibility for his own rehabilitation.

**Carroll emphasized the importance of specializing.** While all blind people are not the same, the big difference is between the congenital and adventitiously blinded. It makes a big difference on how you approach rehabilitation if you are working with someone who is newly blinded or with someone who has been blinded for twenty years. In developing St. Paul's he certainly went against the times in that he developed a program that was going to serve very few people, all of whom shared some similarity in terms of the onset of blindness and their age. He did not emphasize numbers. I don't know what the size of a class was at St. Paul's; I presume it was around 15 or 20. At Pittsburgh Guild, where I worked, it was always 16, as I remember, in those days. Carroll, therefore, could not boast that he had rehabilitated large numbers. Given the numbers game that existed then, and it may still even exist now, with the importance of claiming how many rehabs you have, a Carroll-type center could not claim large numbers; but, if the program were going to be relevant to the person's needs, then there had to be some homogeneity within the selection of clients. If

blindness was as devastating an experience as Carroll claimed it to be, then the program had to be quite comprehensive and quite intense. By definition, it could not be presented to large numbers of people.

**Carroll emphasized the importance of quality of services.** I presume this preoccupation, which stayed with him until he died, resulted from his experience at Perkins, experience in the military, experience with the veterans and experience in community programs. He thought that the way to increase quality was through education and he advocated developing specialized programs within universities, and he also attempted to enrich the training of the traditional professional, such as in psychology, psychiatry, and social work. I think he did not have much influence on those, although he certainly was influential in establishing the profession of mobility and orientation.

**Now, I'll say a few words about the rehabilitation program.** Given that Carroll defined blindness in terms of the personal response to it, therefore rehabilitation could not be simply a series of skilled training programs. In his mind it had to facilitate the adjustment to the personal experience which Carroll listed in terms of 20 losses plus their concomitant methods of restoration. Rehabilitation became not so much a series of services as a process. It emphasized the enabling, the energizing of the person to take responsibility for himself. Now I think the contrast between the Carroll approach and the traditional approach was nicely emphasized by the definitions for physical medicine. Carroll was emphasizing a process of change within the individual, and the other definitions, Kinson's and Mayer's, were emphasizing a laying on of skills, assuming the person as a passive recipient of these skills. I don't remember Carroll emphasizing something like maximizing the capacity of people and things like that -- the kind of buzz words that are in rehabilitation. Carroll's emphasis was on putting the person in charge of the process. That means that a rehabilitation center has to focus on a process and then the skilled training becomes part of that process. The important thing that had to take place in rehabilitation was the **reshaping of attitudes.** The things that Carroll was continuously trying to overcome were the feeling of helplessness and the feeling of depression in the blind. Much of the process was helping the person develop more self-respect, more confidence and more ambition. And the question is how do you do that? Carroll did not have a cookbook solution but he had the insight to know that in a process with a lot of interaction between clients and staff something good can happen that will begin that process of taking control. Carroll made it clear

that it was the responsibility of the blind person to develop that and it was the responsibility of the staff to do things that enabled that process to go on. So the process of rehabilitation, in a sense, is a developmental process, it's an interactive process. It is certainly not like a school or it's not like a hospital in terms of diagnoses and treatment.

I remember when I was new in the field, Gordon Connor was the Director of the Greater Pittsburgh Guild, and Gordon in those days had the fantasy that he understood Carroll better than Carroll did himself, and that he was creating in Pittsburgh a center that would be more "Carrollian" than St. Paul's. Father Carroll, I understand, was somewhat competitive; I think that the same can't be said of Gordon. But in working with us and in shaping us to be the staff that he wanted, I think we disappointed him. I remember one day he said there are two major obstacles to developing a good rehabilitation program. One is the clients and the other is the staff. The issue is the same - that you have to shape the attitudes of the clients and you have to shape the attitudes of the staff - that, for a staff, participation in rehabilitation is a developmental process; that the clients bring feelings of helplessness, strangeness, some depressive feelings, maybe a desire to run away, to be cared for, and you have to fight that. But the staff bring attitudes to a rehabilitation process which interfere with it: the competition between various professionals, the delusion that the staff knows best, that we can define what the needs of the clients are in spite of what their own personal wants may be. Carroll's introducing group therapy for clients and staff was a rather creative way to deal with that because (and I ran the program for clients' psychotherapy and participated in the staff's) the issues were the same in both - that is, what responsibility do we have to make things better for ourselves and others? We in the staff had to get away from the belief that the problem with the agency was on the part of the administration; administration did not do things right or the clients were not motivated. We in the "pogo" sense had to face the realization that we have met the enemy and he is us.

So that there was continuous dialogue amongst the staff on how we could be more responsible and more effective in our work with the clients, Gordon Connor used to sit in all the time. He made a promise he'd always be there, and he was. He also made another promise that he would never talk, which I think was a great concession. However, it was frustrating, because in our minds many issues could have easily been solved by administration. We would much rather have had administration make a decision and get us out of it. But the issue in



Carroll was always that the person has to take responsibility. And if you ever come to a reunion of people who have worked at the Carroll Center you will find a great deal of affection going back and forth, and I think that comes out of the group psychotherapy. We faced ourselves and we improved. We learned to be less impressed with ourselves and more integrated in the process of helping others.

The other insight that Carroll had, I think, was that the obstacles to rehabilitation are psychological and social; that is, they are psychological in terms of the attitudes and values of the clients and the staff. They're involved in the psychology of the community. They are social in the sense that there is much in the community, there is much in various processes that interfere with rehabilitation. There are other agendas that must be met rather than the needs of the client.

Carroll also saw that the person was also the receptacle of resources, that we, the clients and the staff, were both the obstacle and the assets and the whole process was to help us neutralize those qualities we had that screwed things up and to enhance those personal qualities that make things go better for staff and for clients. Therefore, the psycho-social process was a developmental one for both the clients and for the staff. I tried to take some of Carroll's ideas and put them into a different form that would represent more of a social or organizational approach, and I came up with this definition:

Psycho-social rehabilitation is a process which takes place in an environment created to enhance the competency of the people who participate in it. Clients, staff, students, family and friends participate in learning and in helping each other. Clients gain new skills, new awareness of challenge, responsibilities and opportunities, increased self-respect and a reasonable sense of competence in dealing with the demands and expectations of community living. The staff learn more about how to help clients with different reactions to blindness, how to work cooperatively with people with different interests, values and expectations, how to create and maintain a supportive environment, how to increase their own self-respect and sense of competence. Students learn about blindness, the rehabilitation process, interpersonal relationships, professional behavior and their own reactions to blindness and to other helping professions. Family and friends learn about blindness, the losses it

imposes, the resources available to compensate for the losses and the psychological and social impact of blindness on others as well as on the persons affected. The environment of the agency in which these processes take place is made up of a physical structure, people, procedures and processes. The agency represents the best judgment of responsible leaders about how to combine money, buildings, geography, and personal qualities of the participants into a supportive, challenging, enabling, and satisfying system. Its design aims at maximizing the probability that helpful experiences will occur to all participants, recognizing that some helpful experiences, such as braille classes and skill training sessions, can be planned into the system, while other experiences such as friendships, group support, and personal achievement result from various fortuitous events.

The Center is designed to enhance the probability that enabling experience will occur both within and without the Center. The psycho-social rehabilitation process evaluates itself in various ways. It regularly evaluates both systematic and individual performance with the goal of increasing the effectiveness in achieving the goals of psycho-social rehabilitation. The psycho-social rehabilitation system evaluates personal gains and accomplishments as well as increases in general social and occupational competence. It marks increases and personal confidence in risk-taking behavior and increased concern for and contribution to the welfare of others, as well as the lessening of self-centeredness, dependence, and random hostility. The agency reviews the process of rehabilitation in terms of efficiency, smoothness of operation, relevance to system-wide and individual goals, and its ability to enhance the well-being of all participants. Over a longer period, psycho-social rehabilitation evaluates the behavior of its former clients in the community, marking the degree of personal independence, participation in family and community activities, employment, sense of well-being and general helpfulness to others. It evaluates its effect on staff in terms of professional and personal development concerning staff turnover rates, morale, job satisfaction and the reputation of the Center. It considers these gains against the background of cost, noting changes in cost over time and ways in which some goals could be accomplished with less expense. It notes the long-term effects of psycho-social rehabilitation on the public in terms of its understanding and willingness to continue to support comprehensive psycho-social services for the blind.

Let me close by describing the two principles which I think were basic to understanding Carroll's behavior. I think he was motivated by two ideas: the idea of **justice** and the idea of **charity**: Justice being that everyone deserves the help that he or she needs in order to participate in community living, and charity, that it is the responsibility of all of us to help each other and to be sure that everyone has the resources that he or she needs in order to participate in the community.

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# CHANGING CHARACTERISTICS OF CLIENTELE IN EDUCATION AND REHABILITATION

*Corinne Kirchner, Director of Social Research  
The American Foundation for the Blind*

With limited time at my disposal, I have found that what usually works best is to take a highly concentrated approach. If we are looking for data that directly describes the nation's blind and visually handicapped population, the "orchards are barren." The data is even weaker on the local level where more planning goes on than nationally. However, if we look to general population data from the national consensus and other national sources on general social trends, we have better luck.

For present purposes, using these sources is not going too far afield. First, it is plausible to expect that general social trends will be broadly reflected in the blind client population. Secondly, we do know that the visually handicapped client's profile does in fact differ somewhat from the general population's profile; for example, those who are visually handicapped or blind, as a group, are older and poorer. Still, understanding general trends is necessary because they define the norms and options faced by blind and visually handicapped clients. Ultimately, of course, practitioners working with individuals, none of whom ever matches the societal profile; find all of them are affected by it.

One last introductory point: there are various suitable ways I could have packaged this presentation. I have chosen to do it around what I would call "life-style values", rather than straight "demographics". Demographics enter into this, but my emphasis is on emerging value patterns, and this is futuristic. It is my opinion that emerging value patterns are expressed by demographic groups.

Now, let me list the major points I want to cover just in case I don't have time to cover or develop them all: And they are these:

1. A growing value on lifelong formal education:

2. Increasing diversity in family and household composition and the changing roles associated with those changing living arrangements.

3. An emerging distinction between notions of "health" and "fitness" and the question (and I think it is a very open question)

where do, or where will persons with disabilities fit into those distinctions?

4. An emerging view of disability as the basis for civil rights and for political activism. And in connection with this last item, I hope to get to tell you a little bit about some data that reflect questions about the implications for service delivery when the client is not a charitable object.

Now we will review those points with data.

1. A growing value on lifelong formal education - There are massive and continuing indicators of the increased value being placed on formal education, throughout the life cycle. The impact for practitioners will be felt directly and indirectly - because B/VH clients will not only require the same educational opportunities, regardless of their age, but also their families (parents of young clients; adult children of elderly clients) will more often than in the past be "educated consumers" of professional services.

Personnel preparation programs can make a significant difference in whether professionals view the development of educated consumers as a **threat** or as a **resource**. It may be relatively easy to convince professionals of the benefits of working with clients and families whose education is close to their own level. But increasingly, providers must be prepared to work both with children and adults whose educational and occupational goals may be **higher** in social status than their own. I think it will be trickier to prepare practitioners to have both the attitudes and the skills that will permit them to be equally supportive for clients who are in, or heading for, highly specialized and high-prestige occupations.

I will quickly review the headings under which I have data, and I'll try to restrain myself in reporting too much detail.

**Item Early Education** There is a strong trend in the general population toward starting children in school at very early ages. Take 5-year-olds: between 1970 and 1981, the percentage of all 5-year-olds who were enrolled in school rose from just



under 70% to over 80%. For 4-year-olds, the figure rose from 28% to 45%. And among 3-year-olds, the figures went from 13% in 1970 to 27% in 1981, and are still climbing. (I don't have data for younger ages) (Stat. Abs. 1982-3, Table 223, p. 142).

It is important to recognize that, although this trend is consistent with and perhaps was stimulated by, the massive movement of mothers with young children into the labor force. Nevertheless, the levels of enrollment and the rates of change over the past decade have been just about the same for children of nonworking and working mothers. Furthermore, the general pattern holds up among Blacks as well as Whites. (Stat. Abs. 1982-3, Table 223, p. 142)

Seemingly, as an independent development in special education, early intervention programs (from birth, when possible) with blind and other handicapped children are part of the current growth area. Such programs aim to minimize developmental delays previously found at school ages.

The question facing service delivery is whether the former developmental milestones for non-handicapped children, at least in the social and cognitive areas, will continue to apply, or will move forward as a result of most children's earlier school experience. The concern is that the gap just moves along. Are these early intervention programs aiming toward what are going to be outdated developmental goals?

**Item: Education among young adults:** In the general population of 18 to 24-year-olds, school enrollment rates have fluctuated since 1960, with 1970 a high point, and 1981 somewhat lower but still higher than in 1960. Using 1981 data, about one half of 18 and 19-year-olds were enrolled in school; about one third of 20 and 21-year-olds; and about 20% of those 22 to 24-year-olds. The trend of the past two decades partly reflects fluctuating labor market conditions, but there seems to be a more basic trend away from lock-step progress from high school through post-secondary education. Increasingly it is not only acceptable but expected that students will undertake full-time work experience before or in the midst of their college or trade school years.

If blind/vh students are to gain the same benefits, both educators and rehabilitation workers will have to modify traditional expectations. In rehabilitation specialty the notion that a job placement, once it is achieved, is a sufficient goal, will have to be tucked away on a very high shelf. Policy and practice will

have to support working clients who want to return to education for retooling in their previous field, or to pursue a new one.

**Item: Education among older adults:** There are two strands of data to consider here. First, the average educational level of younger cohorts has increased regularly; the aging of those cohorts means that the population from whom most newly blind people are drawn i.e., elderly people--will be more highly educated than in the past. Nearly all will have completed high school, and some college will be routine. The exceptions will be concentrated among first generation ethnic minority groups.

The evidence can be stated many ways. Take high school graduation as a bench-mark: in 1960, 41% of adults 25 years or older had completed high school; in 1970, the figure was 55%; in 1981, it was up to 70%. Or take higher education: in 1960, only 16% of all adults 25 years or older had gone beyond high school; in 1970, that figure increased moderately to 21%; by 1981, it jumped to 32%--fully one third of the adult population, and climbing. (Stat. Abs. 1982-83, Table 226, p. 143)

The second strand in this part of the tapestry has to do not with the aging of cohorts, but with current enrollment in education among older persons. Again, there are various indicators: enrollment in school among people in their early 30s is one indicator: in 1960 only 2% of adults 30-34 years old were enrolled in school; by 1970 that doubled to 4%, and by 1981 it almost doubled again to 7%. (Stat. Abs. 1982-83, Table 221, p. 140). The scope of the trend is revealed by the very concept of "adult education"--a definition that encompasses non-degree programs offered outside of primarily educational institutions as well as within them. A special study found that in 1981, 6% of young adults 17-34 years old, and about the same proportion of those 35-54 years old, were in some type of adult education, as were 5% of persons 55 years or older (the figures in each age group were slightly higher among women than men.) (Stat. Abs. 1982-83, Table 286, p. 170). To give some perspective on the last figure, it is instructive to consider that the portion of older adults pursuing adult education. While still a small minority, the number of these adults is about as large as the portion in nursing homes--but we tend to stereotype in terms of the latter.

**2. Diversity in household composition:** Moving close to home in another sense, let's consider living arrangements, more specifically, families and household composition. The trends are

toward diversification away from the still numerically dominant household type, which is a married couple, with or without young children. The demographic trends which feed this diversification are fairly well documented. An amalgam of increased divorce and remarriage rates, high rates of labor force participation by women, later average age at first marriage, improved methods of birth control, liberalized sexual norms, and lower mortality rates among older persons, but the resulting reallocation of family roles both in traditional and newer family types has not yet been well researched.

Because "families" of whatever type define the primary systems in which clients of any age function, service delivery programs need to be concerned with the role-content of the variety of emerging family types. By "role-content", I mean the practical and emotional resources, and the practical and emotional obligations that define family roles.

In the short-run, lacking solid information on those aspects of newer family role-types, it is important for trainees to acquire a basic, not superficial, attitudinal openness. That type of attitude is not easy to achieve. For all of us, our family experience is so fundamental that alternative ways to meet such basic needs are very hard to conceive, much less to accept. But I suggest that, if practitioners operate on the assumption that anything, but the traditional family-type is a "broken" family, their own efforts to establish rapport and build on existing strengths will be shattered. Given the deep emotional basis for attitudes toward family roles, teaching acceptance of diverse types probably will require methods beyond didactic presentation of statistics such as I can present. Role-playing and other methods that Father Carroll implemented with staff would be called for in this area.

Statistical trends in fact are hard to formulate, because the concepts and measures are just beginning to catch up with the changes. The census bureau changed its definitions with the 1980 census, dropping the term "head of household", used for decades to designate the oldest male spouse and define other household members in relation to him. The new concept is "householder", the first adult listed on the census questionnaire, male or female. Also in the 1980s the Census Bureau came up with "POSSLQs, i.e., persons of opposite sex sharing living quarters. Popular culture provides another type, the "odd couple", and other combinations of unrelated adults, not yet reflected in national statistics.

In 1981, about 2 million households consisted of POSSLQs; (Table 58, p.42) about 9 million households had a female householder, no spouse present, of which almost 6 million had one or more children under 18 years old, about 2 million had a male householder, no spouse present, nearly 700,000 of whom lived with children under 18. Between 1970 and 1981, the number of married couple households increased by 10%, but the number of those with young children declined by over 2%. By contrast, the number of female householders with young children nearly doubled and the number of male householders with young children also nearly doubled. The last group, while still relatively small, merely highlights what are more widespread changes in fathers' roles in parenting young children and therefore, changes in the mothers' roles.

In view of the aging of the population, parent-child relationships between two adult generations are of increasing, and poorly understood, significance. Usual modes of presenting census statistics do not yet permit us to capture trends in the number of such families that share households, versus other arrangements. (Stat. Abs. 1982-83, Table 60, p. 43).

### **3. Distinction Between Notions of "Health" and "Fitness":**

It is hard to pull a clear picture out of the nation's health statistics or, more precisely, to assess the implications of various separate aspects. For decades mortality rates have been declining, with consequent increases in average life expectancy, but not in possible life span. Some consequences are well-known, having direct implications for blindness rehabilitation, i.e., absolute and relative growth in the elderly population, amongst whom most new cases of severe visual impairment, generally accompanied by other physical limitations are to be found. Similarly, analysis of health interview data between 1960 and 1981 for children under 18 years old reveal a doubling in the percentage who are reported to have some handicapping condition. Analysts interpret this partly in terms of increased prevalence of physical impairments, but also partly in terms of parents' heightened awareness of special education programming available for children with minor impairments.

When the matter of expectations comes into play in the health status arena, we must recognize the wide thrust of the "fitness" movement. I think this raises a very sensitive question for the disability field and the blindness field. We have here a value



system that is highly visible in our culture. The implications I think are speculative. I've had some people tell me that they fear that what this means is the fitness ideal could counter many other efforts of special education and rehabilitation to promote the social acceptance of people who have any severe physical (or sensory) impairment. On the other hand, I would take a more optimistic view that the separation of health and fitness will promote opportunity for satisfying leisure and improved self-concept of blind and visually handicapped people. The next topic I will touch on is the growing movement of social and political activism among people with disabilities.

My view is that we will see increasing recognition that impairments on the one hand, and fitness on the other, are not inconsistent. This is certainly the message emanating from the growing variety of sports opportunities for visually and other disabled younger adults. It fits also with health interview data from older people which show that about 65% of non-institutionalized people over 65 years in 1981 considered their own health to be "excellent", "very good" or "good" (rather than "fair" or "poor") compared to others of their age (the figure rose among those with higher family incomes). (NCHS-HIS, 1981, reported in US Senate Special Committee on Aging, *Aging America*, 1985-86 Ed.)

Now a brief note on higher income blind persons. I have just completed analyzing some Internal Revenue Service data on people who took the legal blindness exemption on their tax return. Although many of that group do have low incomes, it's a select sub group of legally blind. It includes only people with incomes that require them to file for taxes, and their spouses; no other dependents are in that number nor those who are too poor included because they do not have to file a tax return.

The number of blind tax filers has tripled since 20 years ago, and doubled since about 10 years ago. I doubt that this reflects an underlying prevalence. We do not really know this, since we do not have the underlying prevalence data. This could be reflecting changes in income status and/or household composition and/or age structure, all of which affect having to file for tax returns. I would like to note that in 1983 nearly 25,000 persons who took the blindness exemption had tax reportable incomes of \$40,000 or more. 36 were millionaires.

In the light of the general movement toward client initiative and control in the rehabilitation process, research with that group, and of course I am calling for more research, could be a useful insight. What

will be the rehabilitation goals and professional's role when clients have the wherewithal to buy what they want? Put another way, what would the content and process of rehabilitation be like if, instead of clients having to establish eligibility for free or greatly subsidized services, they could purchase the mix they desired? The rehabilitation professionals might have to establish their eligibility to provide those services.

I suspect that a study of the wealthy few, whom we know from our IRS data analysis do exist, would give clues to the broader question of client controls that are emerging in the field. I will close with a quote that I was quite excited about when I was reading Carroll's book *Blindness* recently. I have to admit, with the implications he foresaw for what I think as perhaps the most exciting development and hard to reflect in demographic trends, the emerging political activism around the civil rights issue.

And this is a quote from Carroll:

*The sociologist of the future, will also perhaps be able to account for the strange fact that in these days of social studies (I think he meant research there) and integration consciousness, the segregation of the blind is still hotly defended and continually promoted. And discover why there is yet so little recognition of the fact that this is a minority group problem, needing the same sort of study and public education as the problem of minority racial and religious groups.*

That was written near the beginning of the black political civil rights activism, a few years before Betty Freidan's *Feminine Mystique* launched the Feminist Movement, and I think both of those are direct models for what is happening now among people with disabilities.

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# THE NEED FOR NEW RESEARCH: STRATEGIES FOR EXPANDING THE PRACTICAL USES OF RESEARCH AND IMPROVING THE SERVICE DELIVERY SYSTEM CENTER

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This presentation focuses on the need for new research initiatives in the field of blindness, particularly applied research that can benefit service delivery systems. Funding sources for applied and basic research projects are briefly discussed, including grants available from the National Institute on Disability and Rehabilitation Research (NIDRR) and the National Eye Institute (NEI). A number of specific suggestions are made that can contribute to more meaningful research which can generate new knowledge in the field of blindness. In addition, research dissemination and utilization models that can impact service delivery systems are briefly reviewed.

I would like to briefly discuss some of the strategies or models that we've used in our agency to promote the use of research findings by field staff. As you know, the two major funding sources for research projects affecting rehabilitation service delivery systems in this country include the National Institute on Disability and Rehabilitation Research (NIDRR which has recently replaced NIHR) and the National Eye Institute, part of the National Institutes of Health. We are very fortunate to have the nation's only Research and Training Center on Blindness and Low Vision in Mississippi for it serves as a valuable resource to our facility staff, field staff, and Business Enterprise Program (BEP) staff. We have one of the nation's highest prevalence and incidence rates of blindness per capita in the U.S., and our clients, like most blind people throughout the country, face major problems of unemployment and under employment. Kirchner and Peterson (1979) reported that about two-thirds of the working age blind/visually impaired population are not working. While a significant number of Americans have irreversible impaired vision and are totally blind, more than 90% retain some degree of usable vision (NSPB, 1980). I find that this tends to hold true for the people we serve throughout the state (i.e., the vast majority have some residual vision).

Given the importance of both basic and applied rehabilitation research, what can Vocational Rehabilitation agencies do to promote meaningful research efforts that will produce new knowledge in a usable form and impact upon the rehabilitation

service delivery system? Part of the answer is based largely on the state vocational rehabilitation director or administrator and his/her recognition that research is an ongoing process; and, in order to be effective, many people in many different roles must be involved. State directors should be encouraged to actively participate in research utilization conferences and/or leadership symposiums such as this. State directors should serve on university advisory committees and encourage doctoral research that will address client problems/needs. Likewise, the state director must recognize the need for longitudinal rehabilitation research projects and commit the support of the agency in terms of generating adequate sample sizes, ensuring counselor cooperation in collecting data and encourage follow-up in-service training programs which focus on subsequent research findings (i.e., new knowledge produced in a usable form is of little value unless it is used). Assistance in generating an adequate sample of subjects can be particularly helpful. Much of the applied research being published on blindness/low vision in this country contains such small numbers that it is often difficult to generalize findings to a larger population.

Agency heads should also support field-initiated research projects or low vision research projects within their state which might be funded by NIDRR or the National Eye Institute. The 1984 amendments to the regulations governing NIDRR established a program of field-initiated research whereby potential investigators are encouraged to generate research ideas based on needs and opportunities as perceived in the field. Application procedures for programs funded by NIDRR require the applicant to submit a copy of the application to the state rehabilitation agency for comment in accordance with EDGAR regulations. "State rehabilitation agency" includes the state agency for the blind if designated as the state agency with respect to that part of the plan relating to rehabilitation of blind individuals (34 CFR 350.4 (b) (2)). This requirement applies to research and training centers, research and demonstration projects, rehabilitation and engineering centers, model research and training programs, dissemination and utilization projects, as well as field-initiated research projects. As a general rule, these applications for federal funds are not subject to



Executive Order 12372 (Intergovernmental Review of Federal Programs) while other eye-related research projects (e.g., construction grants) may be subject to review by the state clearinghouse prior to federal action being taken. VR staff should also be willing to advocate for additional rehabilitation research dollars at both the state and national level. Significant efforts should particularly be geared toward generating support for funding increases for the National Institute on Disability and Rehabilitation Research and the National Eye Institute. Support of these programs could lead to better training programs which in turn could increase the number of "qualified" personnel trained in providing VR services to blind and visually impaired individuals as well as address the issue of funding areas of "personnel shortages". Agency heads should encourage their staff to utilize all outlets for sharing practical uses of research findings and opinions or thoughts on research. For example, our staff are encouraged to utilize JVIB sections such as letters to the Editor, Comment of Short Report Sections, etc. These are designed to publish material or comments that are meaningful to the field but do not meet the rigorous demands of scholarly articles. In addition, practitioners should attend AFB Research/Practice Seminars and publish pertinent material in the AER Yearbook whenever possible (particularly on areas such as work disincentives and upward mobility). Another strategy that we use is to summarize or send copies of pertinent articles to field staff (e.g., Sight saving).

NIDRR annually publishes its proposed funding priorities in the Federal Register. The proposed funding priorities for FY '87 include funding for six fellowships in the following areas:

- 1.Fellow to Study Rehabilitation Facilities
- 2.Fellow to Survey Rehabilitation Research
- 3.Fellow to Study Employment Issues Related to Learning Disabilities
- 4.Fellow in Evaluation of Rehabilitation Technology Research
- 5.Fellow in Rehabilitation Technology Diffusion Networking
- 6.Fellow in Prevention of Secondary Disability (e.g., Compliance Issues)

Rehabilitation agency staff must be vocal in their support of such proposed funding priorities for the blind. The rehabilitation community should also keep in mind that, in many respects, NIDRR is the only organization funding research directly related to vocational rehabilitation programs. It is essential,

therefore, that NIDRR funding priorities focus primarily on topics that can benefit vocational rehabilitation agencies and give lower priority to research topics that do not impact directly on the rehabilitation service delivery system. The rehabilitation community in general, and state VR personnel in particular, can impact on such priorities by generating written comments at the appropriate time.

What can the research community do to enhance the spirit of cooperation between researchers and VR agencies? University researchers should comply with Council of State Administrators of Vocational Rehabilitation (CSAVR) and National Council of State Agencies for the Blind (NCSAB) policies on questionnaires, surveys and requests for information. Both of these Councils encourage State Directors to refuse to pursue any request for information of "national" significance to the state/federal vocational rehabilitation program unless such requests have been cleared through the Council. More specifically, information inquiries of nationwide significance to the vocational rehabilitation program should be submitted to the appropriate CSAVR/NCSAB Standing Committee for consideration and action. This policy applies only to "nationwide" requests and the individual state VR agency remains free to respond to local or in-state requests in whatever manner the State Director desires. The CSAVR Rehabilitation Research Committee is charged with maintaining relationships with rehabilitation research facilities as well as screening surveys, requests for information, etc. University researchers also need to recognize the statutory limitations placed on VR agencies regarding confidentiality and release of client data. Federal regulations (34 CFR 361.49th) permit the release of personal information on VR clients to organizations engaged in research only for purposes directly connected with the administration of the vocational rehabilitation program, or for purposes which would significantly improve the quality of life for handicapped persons, and only if the organization, agency or individual assures that : (1) the information will be used only for the purposes for which it is being provided; (2) the information will be released only to persons officially connected with the research; (3) the information will not be released to the involved individual; (4) the information will be managed in a manner to safeguard confidentiality and (5) the final product will not reveal any personal identifying information without the informed written consent of the involved individual, or his or her representative. These provisions must be met regardless of a university's policies and procedures for the protection of human subjects in research.



University-based rehabilitation researchers should encourage doctoral students to consider dissertation topics that would be eligible for financial support. For example, the AFB supports doctoral research in areas impacting upon people who are blind/visually impaired. The Office of Special Education also supports doctoral research in specific areas of rehabilitation. University researchers should also actively pursue Research Fellowships such as those offered annually by NIDRR. It is essential that rehabilitation research projects be coordinated for more effective programmatic development and to avoid unnecessary duplication or overlap among programs. The Interagency Committee on Handicapped Research (ICHR) has responsibility for coordinating all federal programs, activities and projects with respect to the conduct of research related to the rehabilitation of handicapped individuals. A Subcommittee on Visual Impairments (Blindness and Limited Vision) was established by ICHR in 1983. The Subcommittee has four major objectives:

1. Develop and evaluate non-traditional measures of visual performance and skills.
2. Devise and evaluate different strategies for training individuals to improve the use of their residual vision capacities.
3. Standardize methods of evaluating and specifying devices to aid visually impaired persons.
4. Devise methods to collect clinical information in a more standardized form.

The National Eye Institute is the leading source of support for low vision research (U.S. Department of Health and Human Services, 1983). Limited funding for low vision research is also provided by the National Institute on Aging and the National Institute of Child Health and Human Development, both of the National Institutes of Health; by other organizations within the Department of Health and Human Services such as the National Center for Health Services Research; by organizations within the Department of Education such as NIDRR, Office of Special Education, and the Rehabilitation Services Administration; the Veterans Administration; Department of Defense; and the National Science Foundation.

In the multivolume report of the National Advisory Eye Council entitled Vision Research - A National Plan: 1983-1987, the Report of the Panel on Visual Impairment and its Rehabilitation contained three broad research goals:

1. To advance research designed to enhance the rehabilitation, training, and quality of life of blind and partially sighted persons.
2. To develop methods for specifying and measuring loss of visual function that will improve the characterization and categorization of visual handicaps.
3. To develop improved epidemiologic data for blindness, partial loss of sight, and visual anomalies that will enhance the development of research, training, and service planning functions for these populations.

The Panel also made recommendations to the NEI and other agencies which support such research in this field over the next five years. The research priorities delineated by the Panel include:

1. Study the visual characteristics of individuals with specific types of visual impairment.
2. Conduct research on the optical, electronic, and other rehabilitative requirements to enhance the capabilities of visually impaired persons.
3. Conduct research on basic skills relating to mobility and orientation.
4. Encourage "human engineering" studies that will help people with specific visual impairments to interact more independently with their environment.
5. Conduct epidemiologic studies of the types and extent of visual impairment resulting from a variety of disorders.
6. Develop special contact lenses and other optical aids for patients with corneal or lens problems.
7. Study the effects of prior visual experience on the nature and extent of visual impairment and of the ability of people to cope with their impairment.
8. Study special problems or adaptations required in response to visual impairment in the older population.

I'm convinced that the rehabilitation community and the University based research community can work together more closely to help generate new knowledge that will impact on the employment needs of our blind and visually impaired citizens. We have to be willing to communicate, willing to listen and willing to change. By working together in a cooperative spirit, we can maximize employment through research. As Helen Keller so aptly said, "It's not enough to give the handicapped person life; they must be given a life worth living."

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# IMPLICATIONS OF TECHNOLOGY UPON THE REHABILITATION PROCESS IN THE 21st CENTURY

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Technology can be expanded to have a significant impact upon the rehabilitation of blind and visually impaired individuals in the 21st century. The nature and the extent of this impact, however, must remain speculative because they will be determined by the status of multiple variables at any given time. These variables include:

The demographics of visual impairment;

The rehabilitation outcomes sought;

The status of technology within the society as a whole;

The state of the art and the practice of medical science; and

Sociological and cultural factors reflected in the society's underlying philosophical and attitudinal structures.

The following discussion will attempt to describe a probable status for each of these variables at a time 20 years hence. At the outset, a caveat must be offered. The relative quality of a technology or its application cannot be ascertained without attention to a specific individualized set of conditions. In many of the descriptions that follow of technology and its application on the lives of disabled people, there are examples of situations in which the applied technology will be valuable; but, in others, the technology will tend to exacerbate an already unsatisfactory condition. Professionals engaged in the delivery of rehabilitation services must be aware of individual conditions, needs and preferences as the rehabilitation processing is planned and administered. In the following discussion, a dichotomy of possible expectations for the early 21st century will be offered rather than a single status prediction. Subsequent to these descriptions, an attempt will be made to describe the role of technology in the rehabilitation process within the anticipated societal and cultural milieu.

## **The Demographics of Visual Impairment**

Existing and projected demographic characteristics of visual impairment have been presented in detail elsewhere both for the United States and for the United Kingdom. It is clear from these discussions that recent trends are expected to continue well into the next century. The changing population of blind

and visually impaired persons will certainly have a profound effect upon the nature and scope of rehabilitation services and upon expected outcomes.

In brief, rehabilitation professions in the early 21st century can expect to encounter a caseload of blind and visually impaired individuals who have additional disabling conditions. Dr. Penelope Shore's data from the United Kingdom indicate that 78% of the blind and visually impaired persons sampled from the national registry had at least one additional physical problem. Her data are summarized below: 42% had chronic illness; 11% had an additional physical or sensory impairment; 25% had both chronic illness and an additional impairment; and 22% were characterized as having only a visual impairment. In addition, this data showed that 70% of the total population of visually impaired individuals was over the age of 65. Age, however, was not the predominant factor contributing to the large numbers of secondary physical problems as many younger individuals also reported these disabling conditions.

All projections concerning future demographics of visual impairment suggest that current trends toward increasing numbers of older and multi-handicapped individuals with this population will continue to rise for the foreseeable future. Thus, the statistics reported above may reflect an increasingly negative profile for this population.

## **Rehabilitation Outcomes Sought**

The implications of these demographic data and future projections should be clear for future rehabilitation services. Although there will continue to be a need for strong and assertive vocational rehabilitation services, these must be supplemented more than ever before with other services. Medical rehabilitation, gerontological counseling, independent living training, recreational and leisure time management, and family or living group support are among the major forms of rehabilitation services that must be supplied to meet the needs of the blind and visually impaired population of the 21st century.

Competitive, or even supported, employment cannot be the sole and "end-all" goal of public rehabilitation policy of the future. Two points



must be considered. First, only a relatively low percentage of the blind and visually impaired individuals requiring rehabilitation services could be considered employable. Either age or compounded physical condition would limit employment as a reasonable rehabilitation outcome goal. Second, employment of the future will be considerably altered from that of this century. Fewer and fewer jobs are expected to provide the worker with a satisfactory outlet for personal creativity and self-fulfillment.

Work weeks and working days will be shorter than currently experienced. A higher reliance upon robust and expert systems will exist throughout the work place. Thus, vocational counseling for able-bodied as well as disabled individuals will need to emphasize psychological factors to help dissatisfied workers cope with increased employment-related stress. The personal adjustment difficulties encountered by newly blinded adults may often be superimposed upon an already stress-ridden psyche produced by a dissatisfying, technology-dominated employment history.

The expected and publicly acceptable rehabilitation outcome sought for newly blinded adults of working age often reflects a society's value structure of that culture and time. (A comparison of public attitudes and policies regarding the rehabilitation of disabled people in different countries today can provide the interested observer the basis for understanding this principle and cause for possible concern over future policies with a society dominated by technologically-based economy.) A later section of this paper will examine some additional implications of the rehabilitation outcome question for the future.

### **The Status of Technology with Society as a Whole**

Countless authors have documented the rapidly changing and ever accelerating role of technology in modern society and have prophesied future life styles immersed in electrons, photons, artificial intelligence and robots. The degree of accuracy of many "futurists" has been placed in serious doubt by the decline in the growth of microcomputer sales and a widespread and steadfast resistance to the concept of a "paperless" office. A prime example often cited to demonstrate the societal viscosity being met by those promoting universal reliance upon electronic distribution of information is the fact that almost all of the myriad of glossy computer magazines appear on paper. Nevertheless, it must be acknowledged that technology will become commonplace in most areas of daily life by the beginning of

the 21st century. The question is, "How much of life will revolve around, if not be dominated by, technology?", rather than, "Will technology be important?" The answer to the former question will have direct implications for determining the impact of technology upon the rehabilitation process of the future.

Differences of opinion exist relating to the degree to which technology will prevail in our society in another 20 years. Widespread consensus, however, regarding some specific applications of technology appears to have been attained within the community of futurists representing various disciplines. The following applications of technology can be expected to prevail within our society in another 20 years.

- 1) At least 90% of job stations in the United States will require access to a computer terminal. Without question, blind and visually impaired individuals, equipped with the appropriate computer access technology, will be able to compete for the vast majority of these positions.
- 2) Written material will be distributed primarily in digital form through the use of electronics and photonics and will rely upon innovative storage media such as compact disks that are produced and read through the use of laser systems. These media will provide a display of choice under the control of the reader. The output display could be visual, auditory or tactile, depending upon the needs and preferences of the user.
- 3) Health care will use technology for home monitoring of important medical conditions and for diagnostic and treatment activities in central medical facilities. The steadily rising cost of medical services will be controlled to some degree by the individual use of home medically oriented monitoring and diagnostic equipment that will signal changes in body functions. These devices will also be used to transmit recorded data to health care professionals for remote diagnosis and prescription. With an increasing number of elderly and frail individuals, this type of medical monitoring and intervention is certain to play a significant role throughout society.
- 4) Living environments of the future will feature far more technology than at the present time. Home appliances will not only be "automatic" but they will contain a significant amount of "intelligence" and communication capability. The resident will be able to operate appliances from any location within the home, but a computer system will be used to control the operation and monitor the status of many of these devices automatically. Newly constructed

dwelling will contain special wiring to facilitate these communication and control functions by the end of this century. Special cabling, however, will be available for installation as an option in many other older dwellings to provide these features. Although this technology is being developed for the general public's convenience, it will have great benefit for all disabled or functionally limited people desiring to have remote control over their environments. The input for future environmental control systems will feature many alternatives, but voice recognition systems are developing at an impressive rate. Early in the 21st century continuous speech voice recognition systems should be in place. These will be multi-user systems and they will provide access to innovative environmental control systems. This access will also be available to those with severe motor impairments. It will be readily available for data entry into computers and word processors.

- 5) Educational programs of the future will use an increasing number of technological means to provide tutorial and interactive instruction. Steadily rising reports of tuition charges, school violence and campus vandalism are combining to encourage individuals to seek alternatives for advanced and continuing education rather than in traditional institutional settings. For some time, there has been an increase in the number of students in the United States enrolled in correspondence, or distance, educational programs. A wide variety of programs leading to degrees or certificates exists. The use of interactive computer assisted instruction and tutorial software packages continue to grow in number. Within 20 years, a high percentage of time spent in educational programs should be provided by these technological alternatives.

### **The State-of-the-Art and the Practice of Medical Sciences**

The demographics of visual impairment will undergo periodic, and often dramatic, fluctuations as the state-of-the-art of medical science changes and new intervention strategies are applied. Similar changes in the demographics of visual impairment occurred in the 1940's with the onset of the retrolental fibroplasia epidemic, and again in the 1950's with its decline. The proliferation of successful cataract surgical procedures represents another such example from the 1970's.

Perhaps no new fluctuation in the projected demographics of visual impairment will occur in the next 20 years, but at least four areas of medical science research should produce significant changes in these

data at some time during the 21st century. These research areas and their implications upon the visually impaired population are briefly described below.

- 1) The relentless war against disease continues to bring new victories that will eventually reduce the number of chronic ailments associated with advanced age. Either a disease will be eradicated or the debilitating effects of it will be greatly decreased through new treatments. Currently, visual impairment is commonly experienced by an older person simultaneously with arthritis, rheumatism, diabetes, heart disease or hypertension. In time, medical science can be expected to reduce the effects of all of these diseases to a significant degree. Thus, the needs of the visually impaired older population as a whole will be positively affected.

- 2) Biochemical research is producing one of the fastest growing industries. In time, the results of this research will produce biochemical agents that will significantly reduce the negative effects of the aging process, including effects on memory and intellectual capability. It also should eventually lead to a decrease in chronic illness. Similarly, genetics research--that is already positively affecting the breeding of cattle and the production of hybrid crops--will be used to eradicate the inheritance of genetic deficits and disease susceptibility. At some time in the future, retinitis pigmentosa, for instance, may be another physical anomaly of historic interest. As for now, the timing of such advancements cannot be predicted, but many should appear within the next 50 years if not the next 20.

- 3) Research leading to the regeneration of damaged nerve tissue is progressing dramatically. Work with the implantation of fetal tissue has already shown that damaged neonatal tissues will be positively affected by this technique. The long-term implications of this research upon the repair of congenital or recently damaged retinal or optic nerve tissue cannot be predicted with certainty. Nevertheless, the results to date, and the underlying theories, appear to hold promise for at least infantile tissue regeneration within the next several decades.

- 4) Finally, efforts to develop a visual prosthesis based upon the implantation of arrays of electrodes onto the visual cortex are finally beginning to show some promise. With the use of "depth" electrodes, scientists have encouraging data that may lead to the development of instrumentation that should provide very limited but useful visual information to some newly blinded individuals in the future.



Again, each of these areas of medical science may eventually change the demographic data relating to visual impairment. None, however, can be expected to have a significant effect upon the projections for this population in the next 20 years.

## **Technology and Rehabilitation**

Prior to turning to the fifth and final variable listed as a determinant of future uses of technology within the rehabilitation process--namely, sociological and cultural factors--the probable implications of technology upon the rehabilitation process described in the discussions of the first four variables will be summarized.

Within the context of the projected demographics of visual impairment, rehabilitation professionals 20 years from now should have expanded service responsibilities for a caseload of older, multi-handicapped, visually impaired persons. The rehabilitation needs for these individuals will include: vocational rehabilitation, medical guidance and attention, gerontological counseling, independent living training, assistance in managing recreational and leisure time, and family/living group support. Simultaneously, it is also clear that society as a whole will be using advanced technology in employment, education, home environments, and will be using other technology for regular health maintenance activities.

First, information presented to this point suggests that medical science may reduce the overall affects of some diseases within the next 20 years, but the projected demographics of visual impairment probably will not be affected significantly by these results within this short time frame. Second, the widespread use of many advanced technologies within the general populace will decrease the need for some of the specialized products heretofore emphasized in the rehabilitation of blind and visually impaired persons. The following items will highlight areas in which the merger of technology with rehabilitation needs can be anticipated.

1) Employment will stress the use of computers and electronic information. With the appropriate alternative data presentation system, a blind or visually impaired individual will be able to compete for most of these positions using braille, synthesized speech or large-character displays. One caveat regarding futurists' predictions of increased numbers of people employed to perform their assigned tasks from home using a computer and telecommunication link is in order. These "telecommuters" will add a new and exciting dimension to decentralized work. A danger exists,

however, within the rehabilitation field relating to the potential creation of a stereotyped solution to the employment placement needs of disabled workers. Although telecommuting provides an ideal solution for many individuals who cannot travel under any reasonable circumstance, efforts must be made to avoid isolating disabled people from society even further by indiscriminate use of this employment alternative.

2) Medical technology will be used by many people in society on a daily basis for personal monitoring of bodily functions and changes. These devices will become a key part of health care services in the future. Most of these devices will contain a digital display to be read visually. With the addition of a simple auditory or tactual display, all of these systems will become accessible to blind and visually impaired individuals. Many predictions exist today that suggest that a high-quality synthetic voice output will be a commonplace option for most home aids and appliances in the relatively near future. Blind and visually impaired persons can already monitor blood pressure, glucose levels, weight, temperature and a few additional medically related variables. In the future, these measurements will be considered trivial when compared with the sophistication built into home health-care monitors. Each of these instruments should require only minimal modifications to make them fully accessible to the visually impaired user.

3) Some of the home-based instrumentation discussed in the previous section will contribute significantly to independent living training offered blind and visually impaired adults in the future. In general, home electronics produced for the general public will be appropriate for users who have sensory impairments. Either the devices will have alternative output options--such as speech--or they will be flexible enough to facilitate adaptation necessary to provide full accessibility. Further, the home wiring systems of the future will provide all disabled people, especially those with motor impairments, increased independent environmental control. Without question, independent living training programs will benefit from the fact that clients will have had experience in using much of the existing technology. Emphasis will only have to be placed upon alternative means of finding and operating controls.

4) The use of technology for recreation and other leisure-time pursuits will probably be common for many sighted people in another 20 years. For blind and visually impaired people, on the other hand, recreational uses of technology will be restricted to reading, information acquisition and a limited num-

ber of hobbies and games. The vast majority of other recreational activities engaged in by sighted people using technology will require rapid acquisition of pictorial and graphic information. Although instrumentation should exist that will provide blind and visually impaired individuals access to some two-dimensional displays, the visually compelling nature of the original presentation will probably not be duplicated through another modality. Reading, however, of virtually all material available to the sighted community will be possible independently for blind and visually impaired readers using either electronic reading machines to scan printed documents or through access provided by electronic storage of printed matter. In one of these latter situations, the blind or visually impaired reader will access a computerized data bank using a computer and appropriate display system. In another case, the individual will use a form of reading technology developed for the general public that presents written information that has been stored on a compact disk or other innovative medium using laser systems.

5) In the field of education and other training activities, technology will play an important role for all people as described earlier in this paper. As long as appropriate display technology is available, blind and visually impaired individuals will have equal access to these curricula whenever there is not an overwhelming amount of pictorial and graphic material essential for mastery of the subject. With the knowledge that training materials are becoming more and more pictorial, it can be assumed that there will always be a need for specialized assistance in accessing educational and training materials developed for the general public. Further, there should be a continuing need for specialized curricular materials developed especially for this population of students and trainees. Technology cannot be expected to provide full accessibility to all training materials.

6) In the other areas of future rehabilitation need--those related primarily to counseling and support services--technology can only be expected to play a supplemental role to human intervention. Without question, appropriately developed and selected reading materials and specialized audio-visual-tactual materials can augment didactic instruction, training, or even counseling. The potential danger in this medium, however, as will be elucidated in the final section of this paper, relates to an over-reliance upon this impersonal form of information dissemination. The rehabilitation and educational communities must guard against relying too heavily upon these technological augmentations to human intervention.

## Sociological and Cultural Factors

The fifth and final variable listed earlier as being a determinant of the extent to which technology will impact the rehabilitation process of the future is related to sociological and cultural factors. This variable may be the most important of all those listed because it relates to the question of how society will respond to an increasing reliance and possible dependence upon technology. This presentation will conclude with a discussion of the response that might be realized in another 20 years.

Sociologists and historians point out that, throughout history, the establishment of society's or civilization's socio-economic system has eventually been reflected by a structure of values and mores that tend to support and perpetuate the economy. There is no reason to expect that the emerging information-based economy will not have its characteristic cultural systems as well.

Perhaps the most serious concern relating to the societal response to the proliferation of high technology relates to the possibility--if not the prediction--that people in this era may commonly suffer psychologically from the feeling of alienation caused by the inability to obtain control over personal destiny. Psychologists state that such people may tend to withdraw from one another producing a highly depersonalized society. This concern has been heightened by recent observed manifestations of this behavior within employment settings in which a high percentage of workers appear to experience such feelings and behavioral patterns. These workers do not receive satisfaction from their employment because their assigned tasks do not allow or foster expressions of personal creativity or productivity. Therapists have been retained by businesses to address work-related stress stemming from personal feelings of inadequacy brought about by jobs that lack the desired outlet for personal talent.

A typical scenario would have such an individual withdrawing from others at work and at home or even falling into a depression that can lead to anti-social behavior including violence or substance abuse. This scenario is so closely analogous to that portrayed in Aldous Huxley's *Brave New World*, written 60 years ago, that the causal observer cannot ignore the similarities and the potential implications for the future. The impact of a depersonalized society arising as an outgrowth of over reliance on high technology upon the rehabilitation of visually impaired persons would be negative. Rehabilitation requires empathetic human interaction. A society that produced a depersonalization of human interaction would be pathogenic



rather than therapeutic. The end result would be increased isolation for the visually impaired person. In the worst case, physicians and counselors might use computer-controlled diagnostic instruments that subsequently prescribe and administer therapy. Later, another computer might be used to tutor the individual in a vocation based around telecommuting. Reading as well would be performed with the use of technological marvels. In this scene, a newly blinded individual might be isolated almost completely from other people from the moment that the "rehabilitation" process was initiated. Little if any alternatives would be open to the individual in a highly depersonalized society.

On the other hand, a society grounded upon a high technology-based economy as just described contains the elements that may lead to a higher utilization of "high touch" interaction than in the past. Again, the response of society as a whole to the evolving socio-economic structures will determine which path is followed. With the recognition and the acceptance of the reality that the society and the economy will be permeated with technology, and realizing that a high proportion of employment positions will not provide individual workers self-fulfillment, people may begin to seek personal satisfaction through the expression of creativity and productivity in other avenues of daily life. Such a decision could lead to a shift away from the value structures taught for the past two and a half centuries that emphasize the importance of striving for self-fulfillment within competitive employment settings. In this case, a very different scenario would be developed.

Individuals may well turn to a more productive use of an expanding amount of leisure time for the conduct of humanitarian activities in which they might find the desired self-fulfillment. Disadvantaged groups--including disabled and elderly people--could anticipate an increase in human interaction that in turn would lead to more societal understanding, caring, and acceptance.

In this final scenario, "high touch" could be anticipated to replace high technology at many points in the rehabilitation process and in subsequent daily living activities. Efforts should be made within the professional rehabilitation community to encourage selection of this path of action. Within this format, technology will be playing its appropriate role as an augmentation to human-oriented, client-centered rehabilitation.

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# HOW CAN WE BEST DEVELOP A MULTI-DISCIPLINARY APPROACH FOR THE DELIVERY OF SERVICES TO THE ELDERLY BLIND?

*Douglas Inkster, Assistant Director  
Home for the Aged Blind, Yonkers, New York*

The answer is simple! CASH! Make it extremely financially rewarding for the multi-disciplines to work together to deliver services to older persons with a severe vision handicap. Nothing coordinates like money.

Another way is to find people who will dedicate their life's work to accomplishing that goal in spite of all odds being against them. One cannot help but be impressed with the achievement of religious leaders. Jesus included the blind among his many concerns. For a more recent example, let me read to you the opening statement of the first report of the Society for the Relief of the Destitute Blind of the City of New York and Its Vicinity, dated July 31, 1869:

*"On the first of November, 1868, the Rev. Eastburn Benjamin leased, on his own responsibility, a house on the northeast corner of Second Avenue and 57th Street, for three years, at the rent of \$3,500 per annum, as a home for the blind."*

That organization merged with the New York Infirmary in 1969 and again looked to a man of the cloth for guidance in redirecting their energies. The Hospital Board of Trustees asked Mrs. Lee Johnston, a consultant to organizations dealing with problems of blind persons, about unmet needs in this area. Here is an excerpt from the Board minutes of a meeting held on March 26, 1970.

*"Mrs. Johnston....pointed out that the greatest need for improved services lies with the age group of 50 or older. Mrs. Johnston recommended that some of the members of the committee visit The Catholic Guild for All the Blind, in Boston, which maintains, among other things, the Geriatric Adjustment Center and apparently is the only training center in the country for the elderly blind." (St. Raphael's)*

The members did make that trip to Boston, and the Center for Independent Living came into existence two years later. That began the most exciting and personally rewarding period of my career in the field of rehabilitation of persons with disabilities. I am told that after 36 years in the business, one is

expected to reminisce. Now comes the catharsis. I'm sad and frustrated with the current reactive posture of organizations making up the so-called "blindness system."

It seems that the one thing that our "system" can be depended upon to do in these troubled times is business as usual, and the capacity to do business is diminishing. We are, it appears, becoming more and more satisfied with less and less.

Remember Sgt. Hoover at the Valley Forge Army Hospital and the long cane, the golden years of Mary Switzer because she documented that rehabilitation pays, Father Carroll who was way ahead of his time, Peter Salmon who almost single-handedly created the Helen Keller National Deaf-Blind Center, and Doug MacFarland orchestrating giant strides in service delivery from Washington. Do you, as I do, wonder where the dreamers and shakers are? Is there no one willing to take a risk?

In the world of business, corporations know that, unless they plan for the future, they will have none! They budget for consumer research studies, product development, marketing and service. If they are good at carrying out these tasks, their names become household words, i.e., Xerox, IBM, Avis, Perdue, National Enquirer, etc..

How about us, the blinded system? We conduct research. We know what the needs are. We can even document cost benefits. We also do not want to be confused by the facts. We might have to change some of our thinking, modify some of our programs, perhaps even sell some of our magnificent edifices to respond to what we know. That IS a risk!

Our system, in my estimation, has a lot in common with one of my former supervisors, who said, "Be not first with the latest, nor last with the oldest." What an exciting career he must have had! What an exciting image we must present to our various publics! Oh Father Carroll, where are you?

Here it is late in the twentieth century and we still spend huge sums on nineteenth century programs. How much money does our "system" spend to

provide summer vacations for, as one agency board member said, "our blind people." It IS easier to offer meals-on-wheels than provide rehabilitation teaching in the community . . . and best of all, that person becomes dependent on us! The number of people we "serve" increases! We now really feel needed! We feel good! We have delivered another food basket to the less fortunate. Why is it that an image of zoo keepers comes to mind? Zoos are really not for animal, and far too many of our programs are really not for our consumer services.

In England as well as in the colonies (USA), two out of every three of our consumers are in the third trimester of their life. We know well the etiology of their blindness. We know the importance of prevention. We know the importance of early intervention. However, our linkages with medicine and the "aging system" are remarkably sparse. It is easier to wait for the knock on the front door. Oh yes, we also know that two out of three will not knock!

What should we do?

Let me present one controversial proposal for you to debate. Then, if you can, listen with a second ear to the rationale behind the negative responses. One study revealed, reference available on request, that there is an average five-year time span between the time an older person experiences an irreversible vision impairment and the time he or she is linked to any rehabilitation services. The blindness system has known this fact for at least 10 years and, intuitively, probably a great deal longer. So, let us address this serious problem and begin working on early intervention.

I propose that the profession of ophthalmology develop a board certified speciality in vision rehabilitation called, say, a Visiologist. I further propose that the visiologist be skilled in leading a multi-disciplinary team to address the adaptive problems resulting from an irreversible severe vision impairment. The adaptive problems addressed will include, but not necessarily be limited to, medical, psychological, social, functional, and vocational.

The vision rehabilitation team will include such professionals as, in addition to the visiologist, a psychologist, a social worker, a vocational/avocational counselor, a rehabilitation teacher, a mobility instructor, and an optometric low vision specialist. This team will be called into action immediately upon the treating ophthalmologist's decision that the severe vision impairment is not medically reversible. The call

would be in the form of a medical referral to the visiologist and the vision rehabilitation team. All services of the vision rehabilitation team are covered under federal, state, and private medical care plans.

This approach to irreversible impairments is not new. It took Dr. Rusk only twenty-five years to establish the field of rehabilitation medicine to deal with irreversible physical conditions. As an observing person once said, the longest journey begins with the first step. This is one way we can best develop a multi-disciplinary approach for the delivery of services to the elderly blind!

*Mr. Inkster worked as a Rehabilitation Counselor for 13 years before helping to design and build the Illinois Visually Handicapped Institute in 1963. He was Assistant Director of the National Accreditation Council in 1971-72 and served with Father Carroll on a long range planning committee for N.A.C. He directed the Independent Living Center, New York, from 1972-85 and was recently Assistant Director of the Home for Aged Blind, New York. He currently serves as Administrative Consultant for a charitable trust developing policies and procedures.*



# HOW CAN WE BEST DEVELOP A MULTI-DISCIPLINARY APPROACH FOR THE DELIVERY OF SERVICES TO THE ELDERLY BLIND?

*James J. Acton, Chief of Blind Services  
Veterans Hospital, West Haven, Connecticut*

As you can imagine, it is very difficult to know where to begin in this discussion, since the topic of services to the elderly blind is really quite vast. You might not know that sometimes, from perusing the available literature. We see impressive statistics about the large numbers of elderly blind and how their numbers will greatly increase in the coming years, and how we must be prepared to provide services to them. Beyond that, not much shows in the literature about how we will provide those services, who will provide, where, and with what! Since our time today is fairly short, this discussion will be relatively short and something of an outline.

As far as I am concerned, any kind of multi-disciplinary work with the elderly blind, indeed any kind of work with the elderly blind, must have as its goal the adequate functioning of the person in whatever setting or locale is most suitable and appropriate to that person's abilities and desires. For our purposes today, I am arbitrarily and conveniently distinguishing between elderly blind who are in some kind of protective or semi-custodial situation and those who reside independently in an apartment, senior citizen or public housing, their own home-- they may live by themselves or share this kind of residence with a spouse, relative, or perhaps a friend.

Now, this next may sound a little strange, but overall I am less concerned and worried about those elderly blind persons in the protective or semi-custodial situations than I am about the people attempting to live independently. Maybe it is not fair or accurate to say that, but we will anyway. There are elderly blind residing in state hospitals, nursing homes, long-term care facilities of one kind or another, rest homes, boarding homes, State Veterans homes, religious or fraternal facilities. By the way, have you ever noticed what wonderful care some of those groups provide for their older persons, including the handicapped of all kinds? In Wallingford, Connecticut, where I reside, the Masons have the Masonic Home and Hospital where excellent long-term care is provided to their eligible members in a kind and loving setting. The Home for the Aged Blind in Yonkers, New York, sponsored by the Jewish Guild for the Blind, provides a

wonderful setting for older blind and visually impaired persons. And there are others of this kind. In the VA there are Domiciliaries which provide relatively long-term care to mostly an older age group, including the blind; there are also many Nursing Home Care Units which admit blind veterans.

So, there are many elderly blind in many different types of settings as outlined above, some better than others and some with more potential to provide or to have provided rehabilitative services of one kind or another. And, to provide blind rehabilitation kinds of services to them may not be all that difficult in many cases. For today's presentation I have to generalize concerning this area, knowing full well that the picture is much more complex and fraught with rehabilitative peril than I am admitting. Later in this talk an approach to addressing the needs of this group of elderly blind may hopefully surface.

As we approach the group of elderly blind that by choice, by decision, or by circumstance in living independently, for better or for worse, the picture is different. How do we provide adequate multi-disciplinary services to these people so they can maintain themselves in the living situation, safely, comfortably, with relative ease and with maximum dignity? An easy question with a very complex answer or set of answers!

Many years ago our good friend and mentor, Fr. Thomas J. Carroll, saw and foresaw how difficult this work with the elderly blind would be. He felt that a separate rehabilitation setting would be better for the elderly blind, one that would address their needs from the blindness and aging viewpoint. To this end he created at the then Catholic Guild for All the Blind, St. Raphael's Geriatric Adjustment Center. This facility, formerly a rest home for elderly blind Catholic women cared for by the good Sisters of St. Joseph, opened as a rehabilitation operation in March of 1965.

I joined the staff of the Catholic Guild in May of that year and was assigned to teach Orientation and Mobility--Peripatology, if you prefer-- to the elderly blind trainees. After several months I was



transferred to St. Paul's Rehabilitation Center to teach O&M and, as fate would have it, in the summer of 1969 Fr. Carroll invited me to his office and asked if I would be willing to assume the responsibility as Administrator of St. Raphael's. I said "yes". For almost three and a half years I served in that position before moving to West Haven and the VA Blind Rehabilitation Center. Fr. Carroll saw that the problems faced by the elderly blind were distinct, unique, and multiple, requiring a distinct rehabilitation program with unique approaches to solving the multiple problems encountered in aging and blindness. So, from May 1965 up to now, I have worked in residential rehabilitation centers for the visually impaired, and thus tend to speak very much from that viewpoint.

As we look at our present service delivery systems, I believe we have not really advanced very far beyond what we had when I first started at St. Raphael's, which as you know, now no longer exists. The Center for Independent Living in New York offered a fresh approach, with creative thinking and positive ways of approaching the elderly blind. We still have our State Agencies for the Blind and Visually Impaired; state rehabilitation facilities; private agency rehabilitation centers; the VA Blindness System with its residential rehabilitation centers and widespread outpatient services to blinded veterans. And, of course, they all work beautifully together in close cooperation and communication for the best interests of the client; well, most of the time, or maybe some of the time, who knows?

What options in terms of multi-disciplinary services do these various agencies offer to the elderly blind? Residential rehabilitation, a live-in situation; "brown bag" rehabilitation, where the client comes to the rehabilitation center each day and returns home each evening; home rehabilitation provided by a rehabilitation teacher; and maybe that is about it. In my opinion, and of course I am not at all biased, participation by the person in a comprehensive residential rehabilitation program would be the ideal. If the person cannot or will not come to the center, services are frequently provided in the home setting by a rehabilitation teacher, on a more or less effective basis. We have all heard, I am sure, the long sad tales told to us by the rehabilitation teacher who only see a person once a week or twice every other week or once every full moon, or something like that. There are also many blind persons who can relate equally sad stories of missed appointments, sickness, snow storms, cancellations, and on and on. It strikes me as unfair that anything of quality under these circumstances are frequently at best, dismal.

But what if we decided to marshal our resources, pool our talents, make effective and efficient use of our collective manpower? To wit, what if the local state agency for the blind and the local significant rehabilitation agency or agencies, public or private, including the VA, agreed to collectively provide rehabilitation services to the elderly blind within their state or geographic area? Is this possible? Why not? Agreements, understandings, protocols, contracts, etc., can all be worked out and put in place to allow sharing of services, if the individuals involved in decision making decide they want to do it and work at eliminating the bureaucratic road blocks; costs, billing, sharing, co-payments, third-party payments party payments, all can be worked out.

Now, if there were a core rehabilitation facility with a residential rehabilitation component as well as a "brown bag" rehabilitation component, and an intensive staff in-service education program in the dynamics of blindness and rehabilitation, this would be just fine. In addition to a comprehensive rehabilitation program, mini-blind rehabilitation courses could be offered, lasting perhaps three to five weeks, setting the tone and preparing for future rehabilitation endeavors. This facility could serve the rehabilitation needs of many elderly blind persons. However, it would not help those many blind persons who still live independently and cannot or will not come to the rehabilitation facility. For those people, the rehabilitation center may have to go to them. A comprehensive review would certainly identify clusters of elderly blind, probably in large towns and cities and their environs. Satellite rehabilitation teams could be established in these cities on a scheduled basis in a central location. Elderly blind persons could be transported to the satellite by whatever means seems best; taxi, family car, mini-bus, volunteer, what have you. Rehabilitation services would be provided on a scheduled basis and the person could return home at the end of each day.

The satellite team would have a Team Leader who would coordinate activities and the schedule. Other members would include: Orientation and Mobility; Activities of Daily Living; Communications; Low Vision; Social Work; Avocational Skills, including physical education and recreation. A Team of six to eight people should suffice. Clients would perhaps be seen on Monday, Wednesday, and Friday. Tuesday and Thursday would be reserved for those elderly blind who cannot or will not come to the satellite center. For them the Team will travel to their living locations and provide on-the-spot rehabilitation, a kind of Blind Rehabilitation Swat Team. Depending on the needs of the local clients, two or three Swat Teams could travel out to provide

needed services. These Swat Teams could also travel to local long-term care facilities to work with the institutionalized elderly blind population, as well as staff of those institutions.

In the second week, the first week's schedule would be reversed with outreach rehabilitation services on Monday, Wednesday and Friday, and satellite center services on Tuesday and Thursday. This arrangement would continue until substantial needs were met. Follow-up beyond that would be handled in the usual manner through rehabilitation teachers from an appropriate agency. With its work completed, the Satellite Team would move on to another city or town, or be re-formed into another Team.

Although I am not sure how much Satellite work is being done with regard to blind rehabilitation services, there is nothing startlingly new about Satellite centers in the delivery of aspects of health care. As a quick example, in the state of Connecticut, Yale-New Haven Hospital has entered into a sharing kind of agreement with Gaylord Rehabilitation Hospital, located in Wallingford, Conn., to provide physical medicine services to outpatients referred from various sources. Services will include Physical Therapy, Occupational Therapy, Whirlpool Therapy, Speech Therapy, and others. The costs of renovating the facility have been borne by the two hospitals, and staff from both facilities will be assigned. Lengthy discussions and negotiations were required to accomplish the task but it is a reality; the first patients were accepted this past Monday, November 17, 1986. Satellites will be opened in other major Connecticut cities in time. So, the concept is possible and feasible.

In providing services to the blind and visually impaired and especially to the elderly blind, certain crucial services must be provided before rehabilitation is begun. These sound very obvious, but they are crucial. A full and complete medical examination, with treatment and remediation of any existing conditions and a clear statement of the person's physical limitations, with a physical capacities appraisal; a full and complete ophthalmological examination, with treatment and remediation of any existing conditions; a full and complete optometric/low vision examination with prescription of aids and devices, and recommendations for continued work in the Low Vision Area. The above may sound like a kind of rehabilitative Valhalla. How many times has our work been interrupted or slowed down by medical or physical conditions or problems; or by an ophthalmological examination performed when rehabilitation is partly underway

and an operation or treatment is recommended that precludes further rehabilitation?

Could we envision the core rehabilitation facility for the elderly blind mentioned above, attached to and proximal to a first-class medical facility, yet at the same time functioning autonomously with a blind rehabilitation person as Administrator? Blind persons entering the rehabilitation facility would receive an initial complete physical examination and history performed by the medical facility physician assigned to the rehabilitation center; consultations would be initiated as appropriate to the various clinics and sections of the medical facility. An ophthalmological examination would be performed, as well as the optometric/low vision examination. All this would hopefully be completed within the first two weeks of the program. Within that time frame, Nursing would do their nursing history, the person would be seen by Dental, the Dietician/Nutritionist, and any other therapy area that seems appropriate or necessary.

While the above process is underway, the elderly blind person would receive initial evaluation and instruction from blind rehabilitation staff, especially in Basic Skills of Orientation and Mobility, Activities of Daily Living. The entire process should take two to three weeks. Subsequently the person will proceed on in the rehabilitation program. However, as we have said, not all persons may wish to stay in the residential or "brown bag" program for an extended period. They may wish to return home and receive services there. So be it.

An intensive evaluation as outlined above would set a good foundation for rehabilitation efforts. Many elderly blind persons, perhaps most, may be willing to accept a short-term intensive commitment as a start to further efforts at-home or in a Satellite Center. In my experience, the older blind person can accomplish much with the help of the medical doctor and the guidance and compassion of the professional nurse. Their combined efforts can do much to assure successful outcomes in rehabilitation. Also, the low vision optometrist can assure and reassure the person concerning his/her vision, its present functioning, and what he/she can reasonably expect to attain in low vision.

Well, we have tried to present various options for the elderly blind person that may still involve a multi-disciplinary approach, or something close to it: residential rehabilitation; mini-blind rehabilitation programs; "brown bag" rehabilitation; satellite blind rehabilitation centers, blind rehabilitation SWAT teams. They give us a number of ap-



proaches to the client that may stimulate interest and motivate participation.

The effort is not simple, since it can easily become scattered and uncoordinated. As services move farther from the core rehabilitation center, they may become more difficult to coordinate; as the services move out from the satellite center, they may become more singular, one-dimensional, and less multi-disciplinary. Sharing of staff and resources between and among agencies may allow for the versatility, knowledge, and manpower needs necessary to carry out adequate rehabilitation programs.

Work with our elderly blind clientele can be as challenging and rewarding as work with any age group or population. And, if any age group deserves the attention of a multi-disciplinary, coordinated team of highly experienced professional rehabilitation workers, it is the elderly blind. They do not need mobility aids, or peripatologists with a small "p", or rehabilitation assistants, or pseudo-professionals; they deserve the best our professions have to offer. Let us be creative, original, and perhaps a little daring in our work and approach. The effort is indeed well worth it.

*Mr. Acton is currently Chief of Blind Services of the West Haven Veteran's Hospital, Connecticut. Mr. Acton was trained as a Peripatologist at Boston College and taught Orientation and Mobility at the Catholic Guild for the Blind under the directions of Father Thomas J. Carroll. He later went on to become the Administrator of the St. Raphael's Geriatric Center, a program at the Catholic Guild that was one of the first to deal with the problems of aging and vision loss in a comprehensive, residential environment.*



# USING SUCCESSFUL CLIENTS TO MARKET SERVICES

*Samuel Genensky, Ph. D. , Executive Director  
Center for the Partially Sighted, Santa Monica, California*

It is my understanding that Mrs. Rachel E. Rosenbaum, the Executive Director of the Carroll Center, would like me to tell the assembled about our **peer counseling program's Speakers Bureau and about what impact it has had on publicizing Center services, about fundraising, and about getting patients to the Center for assistance.** I told her that I would be willing to address these topics, but that I felt that the basic issue is one of how does one market Center Services. How does one make one's case with various sources of referral such as ophthalmologists, optometrists, departments of rehabilitation, commissions for the blind, departments of education, school systems, the general public, etc.

In my presentation I shall talk about our Speakers Bureau, what we have done to try to reach the members of the ophthalmological community, what we have done to reach the optometric community, what we have done to reach the legislature and through it the California Department of Rehabilitation, what we have done to reach local school systems and what we have done to reach the general public.

## Speakers Bureau

This is a group of former and continuing patients of the Center who are interested in public speaking, who are reasonably competent speakers, and who are not beset with problems that would have a negative effect upon what they say in the course of their speaking in the name of and in behalf of the Center.

The Speakers Bureau is run by one of the patient volunteers, Mr. Lincoln Moss, but is supervised by at least one of the members of our clinical psychological staff. The Speaker usually goes out and gives talks in the company of a Center staff member who supplies the speaker with transportation and who may share the speaking duties with the patient's volunteer. Speakers usually talk about what they have done to help themselves, about what the Center has done for them and about the Center and its service mix.

The Speakers Bureau is an **informational entity.** It is **not** in the business of fundraising or of patient acquisition. However, if the Center should receive funds as a result of a presentation by

a member of the Speakers Bureau, we do not turn down the donation. Similarly, if persons are inspired to turn to the Center for assistance as a result of hearing a member of the Speakers Bureau, we are more than delighted to help them.

The supervision by the psychological staff involves helping and advising the members of the Speakers Bureau as to what they might consider covering in their presentations and how they might say what they (the speakers) wish to say in a way that is informative, non-inflammatory, constructive, useful and helpful to the partially-sighted and to the Center.

## Outreach to Ophthalmologists

There are more than 600 ophthalmologists in Los Angeles County which has a population in excess of 8 million people. One ophthalmologist told me that if another ophthalmologist goes in practice in the County, he or she had better be prepared to have a practice that consists of patients who are themselves ophthalmologists. Our Center obtains referrals from between 100 and 125 of the County's ophthalmologists. I phone as many of the ophthalmologists as I can. Those who already refer to the Center, I call and thank. I ask them to continue referring patients to the Center and I ask them whether they have any comments, complaints or suggestions. Those who have not as yet referred patients to the Center, I briefly enlighten as to what the Center is, who it serves, and what services it supplies; I ask them to make referrals to us and I immediately write to them. In my letter I tell them in detail about the Center, about its services, about our policy of always referring patients back to the referring doctor unless otherwise instructed by that doctor, about the fact that they will receive a written report on what the Center has done for the patient, and about the fact that I would like the doctor to visit the Center.

Doctors' attitudes about the Center: Some think the Center is terrific, some claim to know nothing about it, some dislike optometrists and will refer none of their patients to "them" or to a place that utilizes their services; some have simplistic and very narrow views of what the Center does, many are indifferent to its existence and what it might do for their patients, and a few are very hostile toward it.

We try to get out a mailing to every ophthalmologist in the County at least once or twice a year. Whether this mailing does any good or not, I am not sure. Even so, if it creates interest in the Center by even a few ophthalmologists who have not as yet referred patients to the Center and if it stimulates a few ophthalmologists who have sent patients to the Center in the past, it is probably worth the time and money.

### **Outreach to Optometrists**

The Center receives very few referrals from optometrists. I really don't know why this is so; however, I suspect that it is due to several factors, namely:

1. Optometrists see very few patients who are partially sighted. Partially-sighted people usually end up at the office of an ophthalmologist.
2. Optometrists prefer referring to optometrists in private practice rather than to optometrists who perform their duties as a center or clinic.
3. Optometrists are no more caring for their partially-sighted patients than are ophthalmologists and hence many of them are indifferent to what happens to those of their patients whom they personally can't help.

As in the case of ophthalmologists, we have tried to reach the more than 1,100 optometrists who practice in Los Angeles County by mail. In our recent mailings we have emphasized our non-optometric services in order to make clear to the optometrists that we are not trying to do them or their colleagues out of business and, as a consequence, would be quite happy to give only non-optometric services to their patients if that would make them (the optometrists) more comfortable. Besides, it is a well established fact that ophthalmologists are, as a rule, reluctant to refer patients to optometrists, and hence since most of our patients come to us via referrals from ophthalmologists, we are in competition with optometrists to only a minor extent.

### **Outreach to the California Department of Rehabilitation**

We send mailings to district administrators, rehabilitation counselors, and teacher counselors who work for the California Department of Rehabilitation (CDR) in and near Los Angeles County. In those mailings we point out that the Center has financial support from the legislature of the State of California via CDR, and that, as a

consequence, we do not charge fees for care given to CDR clients. We also point out that the cost of serving a CDR client at our Center is much less than the cost of serving that client by any alternative means. We also hold periodic meetings with CDR personnel at which we inform them of our services, and of the fact that their clients can be served at our Center at lower cost than at any alternative facility or private practice.

### **Outreach to Agencies Serving the Partially-Sighted and the Functionally Blind.**

I am pleased to report that our Center has an excellent relationship with the Blind Children's Center and the Foundation for the Junior Blind in Los Angeles. The former is an organization that serves partially-sighted and functionally blind children between birth and about six years old, and it also serves the parents of those children. The latter is an organization that serves partially-sighted and functionally blind children from birth up to early adulthood. It also has a program for adults that is funded by the CDR and is called the Vocational Independence Program (VIP). Our Center serves (1) all the partially-sighted participants in the VIP, (2) all the multiply handicapped children served by the Foundation who have or who are suspected of having some residual vision and (3) various children who are also served by the Blind Children's Center.

### **Outreach School System**

We have tried to reach out to school systems via talks at the Los Angeles City Day School for The Partially Sighted and The Functionally Blind, i. e., The Francis Blind School; talks to principals of schools that have programs for the "the handicapped"; and private presentations to officials of the Los Angeles City and the Los Angeles County Unified School Districts. We have written to these and other school districts, and asked to be permitted to speak to the parents of their partially sighted children, but with very little success. We do get referrals from the smaller independent school districts in and around Los Angeles County, but the Los Angeles City and the Los Angeles County Unified School Districts just don't give a hoot about getting competent low vision care for their partially-sighted students. They are only fearful that if parents get wind of the value of low vision visual care, then the parents will be on the school systems to provide or at least pay for that care for their children. Hence the large Los Angeles Unified School District have decided to go very slow on telling parents about low vision visual care and its



potential value for their partially-sighted children. I regard the attitude of the Los Angeles City and the Los Angeles County Unified School Districts as being at a minimum deplorable.

### **Community Outreach**

We reach our community, namely, the greater Los Angeles area, via newspaper articles and stories, radio interviews and public service announcements (PSAs), television interviews and PSAs, lectures to various service clubs, hospital staffs, senior service centers, homes for the elderly, etc.

### **What Has Worked And What Has Not Worked So Well:**

**What has worked:** Features on the Center that have appeared on TV news magazines at about 7:30 in the evening, feature articles in a section of the Los Angeles Times that is available for reading in every portion of the Los Angeles County, letters to the editor in Modern Maturity and a feature article that appeared in Reader's Digest.

**What has worked to a lesser extent:** Radio PSAs, interviews on radio, interviews on TV that appear on non-network TV stations or on any TV stations that airs the program at some god-awful hour, segments on evening and morning TV newscasts, articles in good, but small, circulation papers or magazines.

**What has failed:** Modest attempts at paid advertising, and articles in ophthalmological and optometric publications.

**What is still to prove itself on account of the fact that we haven't tested it as yet:** TV that involve well-known and perhaps not so well-known TV personalities.

**Getting Patients to and from the Center for Assistance:** Getting patients to and from the Center for assistance is and will continue to be one of the most serious problems for our Center. We need a van or vans to carry our patients to and from the Center. We are trying to get one while at the same time recognizing the fact that purchasing and maintaining a van is a very expensive proposition. Not only does one have to find the money to purchase the van, but one must also have money to insure the van, to hire a driver, to pay for various licenses and to maintain the vehicle over the years. Currently, we hire a vehicle on those days that we know we need one and we have a driver who is available on very short notice. While this is not

the best arrangement possible, it works; the driver is happy, the patients are happy and the patients are getting the help they need to make it in society.

*Dr. Genesky is the Executive Director and President of the Center for the Partially Sighted, Santa Monica, California, a multidisciplinary facility that provides clinical services to partially sighted persons.*

*He received his doctorate in Applied Mathematics from Brown University and he currently serves as Visiting Lecturer in the UCLA School of Medicine, Department of Ophthalmology. He is also currently a member of the National Research Council Commission on Aging Workers and Visual Impairment, and the Task Force on Low Vision at the American Foundation for the Blind. He was the founding president of the Council of Citizens with Low Vision, a national advocacy group.*

*Dr. Genesky has served on numerous national committees concerned with providing meaningful services to individuals with low vision and has authored many publications on this subject.*

*Prior to his research on behalf of the visually impaired, Dr. Genesky was on the staff of the Rand Corporation where he played a key role in developing Rand's efforts to apply military research to non-military national problems. Dr. Genesky has continued this pursuit through his in depth involvement with the research and development of electronic and optical devices that provide assistance to the visually impaired person. His knowledge and expertise in this area has earned him national recognition.*



# RESEARCH FOR THE VISUALLY IMPAIRED

*Carl Kupfer, M.D., Director  
National Eye Institute, Washington, D. C.*

Thank you. I am especially pleased to be with you on the occasion of the 50th Anniversary of the Center and to be able to honor my good friend, Dick Hoover. Like so many of you who were inspired by Dick Hoover to care about improving services for visually impaired people, I, too, have tried to carry his message into the arena in which I operate. That is, of course, the vision research community, a group that has not traditionally thought of rehabilitation as a primary target for its efforts. But we at the National Eye Institute recognized very early that one of our key tasks was to determine what new information was needed to help visually impaired people-- the problems that needed to be, and could be addressed through research.

A major stimulus for our program in visual impairment was a workshop that Dick Hoover chaired for us in 1977. It summarized progress and identified needs for future research. Several years later that planning effort culminated in a special volume of the National Advisory Eye Council's five-year research plan. This portion of the plan is addressed solely to visual impairment and its rehabilitation. It makes a strong case for a greater research investment in this area. In fact, on the basis of the plan, the National Advisory Eye Council has designated research in this area as having strong programmatic relevance. This means that grant applications related to visual impairment and rehabilitation are given special consideration for funding.

As a result, the National Blind Institute's portfolio of grants on low vision and blindness has increased from 4 grants at a total cost of \$166,000 in Fiscal Year 1981 to 23 grants at total cost of \$3,194,500 in Fiscal Year 1986. This represents almost a 2000 percent increase in resources devoted to rehabilitation research during a period when the National Eye Institute's total budget increased by a more modest 58 percent.

But I think you will be more pleased at the philosophy that underlies this program. Let me begin with the plan, which emphasizes a number of topics that have long been of special concern to me. The first is the need to build collaborative teams of experts from a wide variety of disciplines related to vision care--not just ophthalmologists and optometrists, but basic visual scientists, rehabilitation engineers, and rehabilitation specialists as well.

Another major thrust of the plan is its emphasis on the needs of the eleven million visually impaired people who retain varying amounts of useful vision. For this group, two research areas are highlighted as being in need of intensive effort. One is to develop a wider range of visual function tests that can be used, in addition to visual acuity measures to better evaluate the performance and needs of individual patients. In particular, the plan recognizes that we need a standardized battery of visual function tests which will gauge people's ability to perform the tasks they actually care about in their daily lives.

Development of such tests is a prerequisite for another research task identified in the plan--the standardized evaluation of new visual aids. The need for this is clear whenever a new aid appears on the market, claiming superiority over existing devices or addressing an entirely new function. The fact that we have no standardized evaluation of these aids-- but often have to use a trial-and-error approach-- is burdensome to us and to our patients. Clearly, we need some benchmark visual function tests in addition to visual activity against which to judge the performance of the new and existing aids for individual patients.

The National Eye Institute has taken a considerable initiative in seeing to it that these and other recommendations of the plan are put into effect. For example, in order to stimulate research on evaluating visual function in real life settings, the National Eye Institute last year issued a special request for applications on this topic. As a result, eight projects were funded by the National Eye Institute, and an additional project was funded by the National Institute on Aging. These projects include laboratory and clinical tests that will be correlated with performance on such tasks as reading, face and symbol recognition, mobility, and balance and equilibrium.

Also, in attempting to recruit new kinds of expertise for visual rehabilitation research, the National Eye Institute has made use of the Small Business Innovative Research Program. This is a new mechanism for funding that was mandated for several federal agencies a few years ago. The NEI solicitation for research grant applications from small businesses specifically mentioned visual impairment as a topic of interest, and the result was an unexpected influx of talent: A number of high-

quality investigators were attracted by our solicitation. In fiscal year 1986 the NEI funded six projects specifically related to visual impairment under this program.

One of these projects will develop a low-cost optical, character-recognition reader with the potential for either enlarged print or voice output; another project will develop a glare testing device; a third project will develop cosmetically acceptable telescopic aids; a fourth project will develop tactile paper that also enhances the visual image for low vision users, and so on. Without this program, the engineering, electronic, and optical talent represented in these grants would not have been applied to the problems of visually impaired people.

You may rest assured, though, that an important criterion for the development phase of these grants is the involvement of clinical and rehabilitation personnel. This is to ensure that the devices that are developed will actually be useful to visually impaired clients. We already have enough well-intentioned devices going unused. This multidisciplinary approach will be increasingly necessary to progress in the years ahead. That will be the case whether we are talking about high-technology devices or about simple behavioral or environmental modifications to ease the burden that visual impairment imposes on the individual and the larger society.

It is certainly true that not all, but most, improvements in rehabilitative services to visually impaired clients will involve technologically oriented approaches. But there is clearly a role to be played by the scientific and engineering communities. However, we must be careful to ensure that the devices which are developed are responsive to the actual needs of a significant sector of the visually impaired population. They must not be directed solely to the perceived needs of the inventor's visually impaired friend, relative, or neighbor. Assessing the potential market for a device is therefore an important step in evaluating the likely utility of an aid and requires consumer and rehabilitation specialist consultation from the very beginning of any project.

I have been emphasizing the need for cooperation and collaboration among the various research communities in addressing the needs of visually impaired people. I should also point out that the government is actually following its own advice in this regard. There is active cooperation among the various federal agencies involved in visual rehabilitative research through the Subcommittee on Visual Impairment and Blindness of the Interagency

Committee on Handicapped Research. Also, these agencies cooperate through their respective support of the activities of the Committee on Vision of the National Academy of Sciences. The latter group just issued a report on new directions for research on electronic travel aids.

In addition, the results of a workshop sponsored by several federal agencies to identify priority opportunities for the application of technology to meet the needs of the visually impaired elderly have just been published. Two members of the National Advisory Eye Council and one of our National Eye Institute staff members played important roles in that effort. The goal was to draw up specifications of a few problems that might be amenable to solution through application of technology developed for entirely different purposes by NASA engineers. Tasks were considered under four headings: reading; visual discrimination under conditions of low illumination; near tasks other than reading; and spatial orientation. Recommendations included the need for improved telescopes, electro-optical image-processing devices, simulators for training and assessment of low vision clients, and a standardized vision assessment device. We hope that continued cooperation among the agencies will result in solutions to these important problems.

Now I would like to address one further aspect of this collaborative effort: If we succeed in stimulating the needed research on visual impairment and its rehabilitation, and if our grantees are successful in carrying out that research, then it will be even more essential that we have the active collaboration of the service delivery community. These are the people who will be translating research results into practical assistance for clients. To discharge this responsibility, eye care specialists will have to be better informed about the local rehabilitation agencies and national organizations that can provide direct service and support to their patients. Also, both doctors and rehabilitation specialists will need to be more knowledgeable about the devices that are available and might be of benefit to particular clients. Active training through the relevant professional organizations must be enhanced to achieve this goal. We must not assume that practitioners will seek the information on their own. Instead, we must aggressively provide it.

Dick Hoover was a model of the gifted and caring provider of services for the visually impaired. I am glad that he is being remembered here, and I am certain that his example is one that thousands of eye care and low vision specialists should have before them in the years to come.

*Dr. Kupfer is Director of the National Eye Institute. He is a graduate of John Hopkins Medical School and was appointed to the American Board of Ophthalmology in 1958.*

*Prior to his current position, Dr. Kupfer has served as Assistant Professor of Ophthalmology at Harvard Medical School and later as Professor and Chairman of Ophthalmology at the University of Washington's School of Medicine.*

*Noted among his numerous awards in public service are the Migel Medal from the American Foundation for the Blind in 1976, Public Service Award in Ophthalmology in 1983 and the Mildred Weisenfeld Award for Excellence in Ophthalmology in 1987*

*Dr. Kupfer has lectured throughout the world and is highly regarded for his untiring efforts of improving the care and treatment of persons with vision problems.*



# WHY VISION REHABILITATION BELONGS IN A RESIDENCY TRAINING PROGRAM

*Dagmar Friedman, Adjunct Professor  
Boston University School of Medicine*

Today I want to discuss with you why I believe vision rehabilitation care belongs in an ophthalmology residency training program. Vision rehabilitation services are also appropriate in other sites, such as comprehensive rehabilitation agencies, optometry clinics, HMOs, private practice associations, for profit corporations or nursing homes. Low vision services should be delivered wherever there are significant numbers of visually impaired patients and skilled professionals available to provide those services. The importance, however, of involving the ophthalmologist in the rehabilitation system makes it crucial, I believe, to have vision rehabilitation an integral part of residency training.

I will begin today by discussing the significant problems facing both ophthalmology and rehabilitation which make their mutual involvement necessary. I will also highlight specific rehabilitation problems associated with the ophthalmologist and conclude with a discussion of residency training and the role vision rehabilitation training could play in the practice of ophthalmology.

**1. Increasing numbers of visually impaired persons** Improved public health and technology have significantly increased life expectancy. Individuals who survive illness, injury or prematurely increasingly live with complications and permanent impairments. There are an increasing number of patients with severe visual impairments for whom there is currently no helpful surgical or medical intervention. Approximately two million of them could be helped by low vision care. Most of these individuals, however, are not properly identified; they often either go without rehabilitation assistance or receive inadequate care. Many are even told that there is nothing more that can be done to help. (Genensky, 78, Stetten, 81). This is particularly true for those over 65 who experience more low vision than other age groups (Kirchner, 85). In fact, one out of five adults over 65 can be expected to have a severe vision impairment. (U.S. House of Representatives, 1976)

**2. Uneven quality of low vision care.** Over the past decade the number of low vision services has doubled. (Kirchner, 85) Also there is an increasing number of vision rehabilitation specialists. This growth reflects greater interest in vi-

sion rehabilitation and the growing acceptance of its importance. The quality of these services is, however, often inadequate despite the existence of appropriate standards. (Jahoda et al, 81) Lack of administrative support, inadequate reimbursement for offered services, poorly trained staff, little coordination with existing community resources and the small number of involved ophthalmologists make high-quality accessible low vision care unlikely. (Osti, 71, Stetten, 81)

**3. Different focus.** Medical and surgical care traditionally focuses on the diagnosis of a problem or condition and the provision of therapeutic interventions designed to relieve the problem or condition. Care of the visually impaired person requires physicians to work closely with non-physician providers--a relationship which is often difficult. Few ophthalmologists have developed the skills of working with non-medical professionals. Rather than emphasizing diagnostic and therapeutic procedures, which are no longer useful or appropriate, rehabilitation focuses on adjustment to the impairment, restoration of function and the learning of new skills and techniques. (Gritzer et al, 85) How is the patient managing, what capacities remain and what is possible for the individual to do?

What does he or she want to do? Increasingly the rehabilitation patient is involved in the planning of his or her care. This process generally requires a level of physician's training. (Grotzer et al, 85) Too little attention has been devoted to developing the basic knowledge and skills relating to the management of problems common to patients with vision impairment. (Greenblatt, 86)

**4. The growth of corporate medicine.** The lucrative incentive for providers, and the pressure to control costs and to establish efficient business-like management have helped to contribute to the collapse of barriers that traditionally prevented corporate control of health services. (Starr, 82) Medicine is increasingly controlled by large corporations with a profit mentality. Private insurers and employers want medical expenditures to be controlled. The long-term gains to society of a rehabilitated patient may not satisfy the short-term need for a corporation to show a profit to its stockholders or for a hospital to reduce its costs. Thus rehabilitation services may not be seen as cost

effective, particularly if reimbursement does not cover services.

Two-tiered health care, one system for those who can pay or who have adequate insurance and another for those who are poor or uninsured, is likely to become more common.

**5. Increasing specialization and subspecialization.** Specialization and subspecialization tend to weaken the doctor-patient relationship by reducing the scope of the physician's involvement with the patient and increasing his or her reliance on technology. Specialization tends to increase turf issues, often putting barriers between physicians as well as non-physicians and making communication and cooperative planning exceedingly difficult. As the number of ophthalmologists grows, competition for patients will increase. The tension between optometrists and ophthalmologists will also increase. (Gritzer, 85)

**6. Health care rights.** The growing health care rights movement challenges the distribution of power and expertise of the physician. The right to informed consent, the right to refuse treatment, the right to see one's record, the right to participate in therapeutic decisions and the right to due process are challenging the traditional doctor-patient relationship. (Starr, 82, Abrams, 82) Malpractice suits, relatively few in years past, are now more frequent. Failure to inform a patient of his or her diagnosis and prognosis, or failure to refer a patient for rehabilitation services, may place a physician at risk for malpractice.

#### **Rehabilitation Problems Associated with the Ophthalmologist.**

Most ophthalmologists, while aware in a general way of the importance and significance of their role in the rehabilitation process, do not behave as if they know or believe it. It is not uncommon for ophthalmologists to follow a legally blind patient for months and yet not have the courage to tell the patient that he or she is legally blind, or to report the patient to state agencies for service or to refer for low vision care. It is not unusual for ophthalmologists to neglect to ask their patients how they are managing and to determine in which areas of their life there may be problems. It is not unusual for an ophthalmologist to stop seeing a patient as soon as surgical or medical therapy is completed, often leaving the patient and family confused, rejected and not knowing where to turn for help or whether help is even available. It is not unusual for an ophthalmologist to be unaware of community

resources that could help or know how to make a referral.

Some ophthalmologists appear insensitive to feelings of loss and grief associated with reduced vision or a poor prognosis. Many confuse services for the blind with those for the partially sighted. Some ophthalmologists have difficulty working with non-physicians and sharing responsibility with a non-medical professional. Written medical information is often barely legible and in such jargon that it is not helpful to the referral agency.

#### **Residency Training, Vision Rehabilitation and the Practice of Ophthalmology.**

The residency is a period of intense training. Young, knowledgeable, but largely inexperienced physicians learn to do things ophthalmologists do. The residency imposes many burdens. There is much to learn in a limited time. The resident must also cope with long hours, fatigue and the pressure of time. The responsibility of learning to care for eye problems, of learning to seek and accept advice, of translating book knowledge into practice, of mastering technical skills, of learning to make difficult judgments, of learning to work within the medical hierarchy and of handling mistakes are all stressful and anxiety producing. (Hingson et al, 85).

A disease process can lead to the virtual destruction of a personality by making performance of usual roles impossible. A person is diminished by loss of function and may feel excluded from participating in life's activities. (Gritzer et al, 85)

The more seasoned house staff should serve as a role model for the less experienced physician and teach the caring as well as curing aspects of eye care. Learning that there are skills and techniques to overcome functional deficits can be as important to a patient's well-being as making a correct diagnosis. How a physician practices is often determined by what and how it is taught during residency. (Abrams, 82).

It is difficult to change the mode of behavior of practitioners by exhortation, courses, articles in journals or talks at professional meetings. In contrast, new ideas and standards of practice can be introduced with relative ease during residency training if (1) the director of the residency program and at least some of the chiefs of service think the expenditure of time and effort in rehabilitation is worthwhile and (2) if there are skilled and committed role models to serve as teachers. If the ophthalmologist in training has the opportunity to



learn by his own experience, the significance of his impact on the rehabilitation of his patient will mean more than a multitude of lectures, articles or books on what he should do (E. Friedman in Osti, 71).

## Conclusion

The present separation of the ophthalmology profession from the field of rehabilitation has had, I believe, an undesirable effect on the quality of patient care and on the practice of ophthalmology.

Severe visual impairment is often devastating. Patients and their families are often in a situation of helplessness and fear. They want a physician they can trust. They need a physician who will encourage them to use fully their remaining capacities and involve them in the crucial decisions so important for their future well-being. Lack of candor about prognosis strips patients of all control over the life still ahead of them. Indiscriminate expressions of hope and reassurance create doubt in patients and their families as to whether or not they can trust their physicians (Cholden, 58, Carroll, 81, Friedman, 74, Katz, 84).

Talking honestly and sensitively with patients takes time, time that is increasingly in short supply.

The increasing number of visually impaired persons, the uneven quality of low vision care available, the difference in focus between medical and rehabilitative care, the growing impact of corporate medicine, increasing specialization and subspecialization and the patient rights movement will continue to complicate the coordination of ophthalmology with rehabilitation. These are difficult times for rehabilitation as well as for ophthalmology. By working together, this current estrangement, I hope, will be a matter of past historical record, not future reality.

I have stressed the importance of developing a vision rehabilitation program within an ophthalmology training program. With meaningful involvement of the ophthalmologist in vision rehabilitation during the early years of his or her training, it is likely that patients will receive appropriate and timely rehabilitative care when they need it.

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*Ms. Friedman has earned a Masters of Social Work degree from University of California at Berkeley and a Masters of Public Health at Columbia University.*

*She has been an outspoken advocate for comprehensive care for low vision persons and has conducted numerous lectures, seminars and training films on vision loss, aging and health education.*

## Group 1 -

*Corinne Kirchner , Director of Social Research*

*The American Foundation for the Blind*

Our group started out by uncovering some disagreement around how widely the "Rehabilitation Center" model should be generalized. I am trying to choose my words carefully here in order not to misrepresent the views of the people who disagree. The thrust of our discussion can be expressed as: "Is this model the best for all demographic groups at all times, under all conditions?" There was some disagreement there, and then we decided to move on to another issue, that of technology

We agreed that it was important, at least for younger blind and visually handicapped people (under 40 years), to be exposed to computers and related technology, because that is the wave of the future. It was noted that at the current time, in a situation where all their non-handicapped peers are getting exposed to such technology, many blind children are being excluded. Here is a situation where the access technology does exist, but the school systems are not prepared. We talked about emerging models to meet that need. Dina Wischkin from the Carroll Center said that they are embarking on a program where they are not only training teachers and the children themselves in the available technologies, but also training the parents so that all bases are covered. This is necessary to insure that the children will get the services when they are in school. Bill Gallagher suggested that perhaps we need something like an "itinerant computer specialist", comparable to the "itinerant teacher" and "itinerant O&M instructor" models in education.

Then we shifted to discussing issues of specialization versus "genericism". (We thought that term was a "neologism" but it turns out to be a word actually used in Britain) and we got some clarification about what Dr. Shore meant yesterday during her

discussion of specialization and her proposal for an ideal model. Dr. Shore had stated that she was against too narrow specialization; we clarified that what she meant by that was the notion of one person or one type of person who is the specialist in every aspect of blindness. This was the "narrow" model to get away from, I think. The model to move toward would be twofold: the specialist in blindness should obtain a more general exposure to the kinds of issues in providing professional services, ranging from assessment, to technical skills, to counseling, etc.; they should get some exposure before they over-specialize. And the generic workers should get some exposure to what the blindness issues are as they go about their work. This would be the kind of "merging" she was calling for. A model used in New Jersey was described in our group where the various blindness specialists have had to learn a little bit more about what each other can offer in order to avoid over-specialization.

We discussed what we felt was the value of "The Carroll Session". We registered a spectrum of very strong values from it, ranging from the emotional impact it had on some of us and the re-affirmation of our commitment to this field to very analytic consequences of the session's questions that we would really like to pursue and answer. We posed the question in the form: "How would Father Carroll, himself, react to the current social situation and service delivery?"

Amazingly, we ended by somehow slipping right back to the question we began with. It was not planned, but there we returned to our debate about the rehabilitation center model, having come full circle, but without consensus.

## Group 2 -

*James Acton, Chief of Blind Services*

*Veterans Hospital, West Haven , Connecticut*

We had trouble getting organized and what we said may sound a bit repetitious. We did refer to Dr. Shore's talk especially some of the figures she gave. on how late people receive services after they become blind. This may be a kind of common problem, not only to the United Kingdom but to the United States. Also, we noted something that struck us as interesting was, Dr. Shore's comment that the kinds

of services delivered may be dictated by the age of a person and the location where the person lives.

After these general beginnings, we did get into the specialist versus generalist argument--the hot topic of the day. You can start a pretty good fight pretty quickly just about any place talking about that. We wonder what does all of this mean - we really did not

come up with an answer. We felt the motivation to hire generalists was administrative and sometimes these decisions on whether to hire specialists or generalists may be made by people who are not really knowledgeable concerning the issue and what it really implies - that there could be a kind of financial motivation at work in the hiring, that could be pennywise and foolish. For example, depending upon the area and what the profession is, a generalist might require a good deal more supervision. So you may save money in one sense and the other sense you really wouldn't because you have to use so darn much supervision. If the field is going to move towards the generalist some kind of minimal standards should be developed.

Another point stressed in our discussion was our role as advocates. To accomplish our goals with those who make decisions with our legislators, we need to

show how rehabilitation can be productive. We need research into specific areas

We discussed the problem of information -- How does a newly blind person discover the information of the resources? Sometimes he doesn't. Then what happened? Sometimes information obtained in piecemeal. There is a need to continue to educate and probably there will be for the rest of the entire history of the world to educate ophthalmologists, particularly while they are in their residency programs concerning rehabilitation, vision loss, low vision clinics that low vision supplements their work and that kind of thing. That's kind of an ongoing process, I guess.

Our group discussed how to provide services to the various ethnic groups that are getting extremely large in the country--the Asians, the Spanish-speaking. They will have quite an impact on our services.

## Group III -

*B. T. Kimbrough, Director of Services*

*Associated Services for the Blind, Philadelphia*

Well, Group III was particularly sparked by the remarks of Dr. Shore and Dr. Scadden. Members of my group empathized with Dr. Shore's frustration about the fragmentation and lack of coordination in the field. The collective response was, "Oh boy, we agree!...and not only that, but, when are we going to do something about it?". A number of members of Group III felt that it's been pretty well established in this field for sometime that this fragmentation exists and that there is a lack of central direction. It seemed imperative to stop agreeing and start figuring out some way to improve the situation.

An example of fragmentation and a certain territoriality is the way in which agencies tend to assess clients as needing what it is they offer. The clients can obviously fall through the cracks in a setting like that, and there was some general agreement in our group that that happens in too many instances.

In regard to Dr. Scadden's remarks, we learned that we would all like to do some more speculating about the future as technology might impact it, accepting for the time-being Dr. Scadden's provocative model concerning the likely consequences of technology on the future. Some of our group members wanted to add speculations about some groups he didn't have time to touch on. For instance.... How will multiply-handicapped persons be impacted? Some of them...and, I might add...some older blind persons...don't want anything to do with a tape recorder at this point. So, how do we get them to accept other technology how do we get them to

use it how do we use it in their behalf? These are some of the questions that obviously need some answers later on. What do we do about the present group of fortunate, or unfortunate, infants who are now surviving in the intense neonatal care--infants who would have died ten years ago-- infants who suffer from a multiplicity of handicaps? Some planning is going to have to be done in their care and in their development; that planning probably cannot wait too much longer. Somebody is going to have to plan for the increase in the number of older persons we've been hearing about for a long time. We're going to have to deal with the fact that older persons means more blind persons on a percentage basis.

What this group wants to recommend is that it is time for this field to fish and cut bait. This means change the very model on which most rehabilitation money turns. The model that says "you're eligible for service if you are ready to work, if you can do effective work". Our group feels that instead of a gainful employment model, we need to talk in terms of a model stressing a maximization of human potential, whether the human-being involved is going to do gainful work, be a primary homemaker, be a fruitful volunteer somewhere, etc., etc. This is something like the model popularized by the United Negro College Fund which said, "A mind is a terrible thing to waste". To change the model is a legislative matter, and that would be no small matter.

It's time to look harder toward changing the model because so many of the clients whom we are serv-



ing are unwilling or unable to engage in work programs now offered. An interesting instance was cited in which the Rehabilitation Services Administration sampled a group of real clients and gave that base-line of clients the chance to engage in a work program, or various work programs of one kind or another. Seventy percent declined; of the thirty percent who said "Yes", twenty percent of those withdrew before any real work was done,

leaving only ten percent who actually went to work and did anything that could be classed as gainful employment when given the opportunity to do that. Clearly, with that kind of statistical result, the model that a successfully rehabilitated client is one you can employ is a model that it's time to question.

## Group IV

*Valerie Konar , Associate Director*

*Massachusetts Association for the Blind*

We agreed on the need for cooperation, coordination and the value of getting together at a meeting like this, especially to meet people from other parts of the country and share our experiences and our concerns.

We discussed technology, its effects on the general population as well as people with disabilities, and the training gap as technology changes. We suggested the need for more education to counselors on how to refer for technology programs. Again, we suggested more cooperation.

We discussed the need for a marketing approach. Each agency focusing on a particular kind of service, and then just deciding what services to provide and developing a marketing plan. We talked about how we need to get Board members and other persons in responsible positions to change their attitude; to develop one that recognizes that in order to provide a quality service, you do need to spend money on staff and training. We saw this as a solution to funding problems and service problems revenue-generating with a quality service, rather than cost saving by reducing expenses.

## Group V

*Fran Weisse , Director Of Public Relations*

*Vision Foundation*

There was some feeling in our group that we had lost strong advocacy on the federal level because of the shift toward generic agencies that are swallowing up specific interests. We did talk about the importance of the client assistance programs that are mandated in every state. We grappled with the grand question of what is rehabilitation anyway and reviewed some of the pros and cons in the argument: generic vs. specific.

We agreed on the need for cooperation, coordination and the value of getting together at a meeting like this, especially to meet people from other parts of the country and share our experiences and our concerns. Sometimes my bias for self-help because that's the kind of organization I work for, and we are working our own self-help group, here, because we are all nodding and sharing experiences, learning from them, and supporting each other. We tried not to get too depressed with some of the down sides of what we're saying about funding and the lack of trained people, but tried to work out some alternative strategies. We discussed questions and concerns about teacher certification and the manpower shortage, especially in rural states or

small states where there may only be two itinerant teachers for a whole state.

We made a plea for not overlooking consumers themselves, listening to them, and using them as advocates for their own services and also for the responsibility of the individual client, him or herself.

Finally, our group had some interesting disagreements. One of our group members was arguing for a grand disability payment scheme through Social Security, or some similar arrangement. We discussed the pluses, the minuses and the disincentives. B.T. just referred to that problem in citing the study where people turn down an opportunity for work because of some kind of disability payments scheme.

We discussed the problems of quality vs. quantity, which we certainly heard yesterday.

## Group VI

*Jeff Moyers, Director of Storer Center*

*The Cleveland Society for the Blind*

Yesterday, we felt we had a good look at a theoretic construct which was historic and looked forward into the future to give us some insights about what is going to happen long range. We felt that there were some immediate short-range issues that we really have to grapple with, particularly with the shifts in demographics involved. The Center-based model is not necessarily appropriate for many of the people that need to be served. Persons with need for Low Vision training and the aging person with multiple disabilities, are not necessarily going to be coming into a comprehensive center-based program. So the Carroll model is something that has to be adapted to today's realities.

Also, the fact that the nature of the blindness system, having been one that arose out of a charity model rather than a medical model, has led to many persons associating blindness-related services with charity rather than an extension of medicine. That, combined with the over-specialization of blindness professionals-- a blessing in terms of getting people who are well qualified in a specific area--makes it difficult to obtain the services of professionals who are well-rounded enough to address the multiplicity of issues that come up when working with a person in a holistic model. We would therefore like to suggest alliance with the medical system that would give a greater bridge of referral and continuum services. We say this while acknowledging that the

medical model itself has become highly segmented and comprehensive services are not found anywhere. However, such an alliance might help people come forward for services-- some people find a stigma being associated with a charity and welfare-oriented agency--persons who have the ability to pay. They would be looking at a fee for service model. This would enable us to increase our fee income while at the same time recognizing that we are dealing with a changing economic group.

We further discussed the need for looking at the issues regarding para-professional training and using the scarce resource of highly specialized professionals as supervisors of para-professionals. This would require a codification of para-professional training programs, an area that is in need of serious study by this field, in order to keep up with the changes in both demography and funding bases.

And, finally, technology is an area that requires attention from the standpoint of service delivery. Advances in computer access systems have not been paralleled by service delivery capability to enable professionals and consumers to be knowledgeable in this selection of the most appropriate access system comprehensive training. This is required for optimum access to the technology for many people, who certainly could benefit in education, employment or personal use.





